FILIAL CARE TO ELDERLY PEOPLE AND ITS LINKS WITH OFFICIAL WELFARE

Carol L. Tozer

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This thesis is my composition and is based entirely upon my research. It has not been submitted for any other degree or professional qualification.

Carol L. Tozer

To the memory of my father, Edward Graham Tozer.

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ABSTRACT OF THESIS

This research addressed the dynamics of filial care to elderly people in the format of care receipt, care provision and their links with official welfare and has been organised around three substantive gaps in the caregiving literature: a lack of knowledge pertaining to the experiences, understandings and preferences of elderly care recipients; the absence of a family unit perspective which catalogues different relatives' caring contributions and charts interpretations of, and reactions to, diverse caregiving practices; and a dearth of data which examine the character and effectiveness of interaction between the provision of family and domiciliary care at the site of care delivery.

The research revealed disjunctures between the objective measurement of functional impairment and elderly participants' continuing abilities and subjective identification of care needs. Such disjunctures stress that elderly people's care needs can be neither standardised nor objectivised but understood only via reference to the structural, affectual and ideological antecedents which characterise elderly peoples' experiences of family care. The idiosyncrasy and volatility of these antecedents, and their impact upon the provision of family care, highlighted the significance of critical review of the orthodoxy surrounding "unshared" family care. While primary filial carer status was not repudiated by either respondent group, second filial carers were frequently accorded a significance that was disproportionate to the level of their care contributions. From the care recipient perspective for instance, presentation of the unequal distribution of care among their adult children was tempered by the rationales provided by way of explanation, even mitigation, as to why care was unequally shared. These rationales highlighted in unequal measure not only the commonality of the twin axioms of care, but also their independence: elderly participants' appreciation of the labour involved in the provision of filial care and acknowledgement of the unequal load carried by different adult children resulted in remarkably parallel appreciation of the emotion of care they attributed to each of their children.

Finally, while family care is accredited as the fulcrum of community care policy and practice, links with official welfare were organised around front-line domiciliary carers rather than management; and even here any links were more haphazard than pre-planned. Rather than family care constituting the context for formal care and official decisions about the allocation of domiciliary services, the data revealed an inverse relationship whereby family carers more commonly reacted to the context set by formal welfare in the form of service types and levels and changes in allocation patterns. Results also confirmed however that respondents' understanding of formal domiciliary services mirrored those they attached to family care and their personal lexicon added substance to demands for the dismantlement of artificial boundaries between the conceptualisation of the two sources of support.

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AN OUTLINE OF THE RESEARCH

> ...there is no consensus among researchers, policy makers, service providers, caregivers or care recipients themselves as to what constitutes family caregiving.
> Stone, 1991, p724.

Introduction

The care of frail elderly people is a principal theme of scholarly debate in social policy and an important component of political and popular discussions about old age. The burgeoning caregiving literature reflects how the necessary social and family care of frail elderly people raises vital and difficult questions about responsibilities and relationships within the family and between the family and the state. Of enormous personal salience to those directly involved, the care of frail elderly people is also significant at the level of the family, the community and society as a whole.

This research involves elderly people and their adult children and addresses their parallel experiences of family and formal care. It examines the motives, predicaments, behaviours and feelings of the receivers of care as well as the givers of care and examines the context they create for the delivery of formal domiciliary services. In short, this research is devoted to examination of the dynamics of filial care to aged parents and its interaction with domiciliary care.

This chapter provides the introduction to the study and establishes its purpose, scope and design. It outlines the major research aims and objectives of the study and provides an overview of the substantive and methodological axioms on which it is based.

Research Aims and Objectives

Three substantive gaps in the caregiving literature provide the impetus to the scope and design of this research. First, the literature has frequently overlooked the experiences and understandings of elderly care receivers. Second, there is very little information concerning the reactions of family members other than predominantly self-defined "primary" carers to the needs of frail elderly relatives. Finally, the absence of a family unit perspective makes for difficulties in exploring and explaining any basis of the relationship between formal care and family care.

The identification, review and consequences of these gaps are the subjects of substantive later chapters but they are important here because they adumbrate the twin aims of this research:

> **an exploration of the dynamics of filial care to aged parents which includes experiences surrounding the receipt of care and the caregiving efforts of non-primary carer adult children;**
> **and**
> **an examination of the interrelationships which characterise the provision of family and formal care.**

The justification of these aims is based first on the need for caregiving research to include the subjective needs, preferences, and experiences of frail elderly care receivers, as well as primary caregivers and other family helpers, in accounts describing and explaining the organisation of family care. This research therefore addresses the dynamics of family care to elderly kin in the form of care receipt, care provision, and secondary assistance. This ensures an holistic perspective of family care as a relational phenomenon whose adequacy, quality and prognosis depends upon the actions, perceptions and circumstances of both care receivers and caregivers.

Second, in terms of the family-formal care interface, the organisation of family care provides the context in which formal services are delivered and its links with official welfare. In order to complete examination of the dynamics of family care therefore, identification of both the role attributed to domiciliary services in the support of care-receivers and their interaction with family care supports is required.

The dual aims of the study break down into six research objectives:

- to describe and explain prevailing patterns of filial care received by elderly parents;
- to identify the caring contribution made by adult children who are not nominated as their parents' primary carers;
- to place the receipt and provision of filial care within its structural, affectual, associational and normative contexts and to isolate any differences in these contexts according to primary and secondary filial support;
- to examine the circumstances under which, and reasons why, social care agencies are contacted for the provision of domiciliary services;
- to chart the levels, types and perceived adequacy of domiciliary services received by frail elderly people; and
- to examine any interaction effects that the provision of domiciliary services has upon the organisation of family care, including expressed preferences regarding the mixture of formal and informal support.

a. Care Receivers and Research Objectives

Elderly people in receipt of family care and formal services are the linchpins of this research: they describe the circumstances under which family care and home care services are received, their reactions to that receipt, and identify family carers to be approached for participation in the study in sampling stage two. The participation of elderly care receivers also determines and informs several objectives of the proposed study.

There are compelling research and ideological reasons and benefits to placing the views and experiences of the elderly receivers of care at the centre of a study of family care. These are presented in brief below and described at length in the chapter 3. The decision to accord such prominence to care receivers however is also based upon a deep seated personal desire to articulate and reflect the preferences, needs and abilities of those all too often ignored because they lack the necessary resources to make themselves heard.

i. Describing the Organisation of Family Care

Elderly care receivers are the best source of information regarding the suitability, adequacy, and quality of family care. Furthermore, where still married, elderly care receivers are key witnesses in the investigation of gender relations in later life where "the stereotypes....no longer applied over large areas of daily life" (Wilson, 1995, p104). Very simply, they are best placed to draw attention to the provision of necessary support as opposed to the (re)workings of the domestic division of labour during old age. As care receivers, elderly people can indicate whether a certain support provided by their family is the result of their own functional inability (the need for care), the result of their own preferences or unwillingness to learn, or received only because of the insistence of the care provider (both of which might rest upon [former] configurations of the domestic division of labour). Exclusive focus upon the provision of informal care is more likely to blur the boundary between necessary care receipt based upon functional difficulty or incapacity and practices predicated on gender differentiation in the domestic division of labour because it fails to adequately capture the influence of the preferences, as compared to assessed needs, of the elderly person upon the supports provided by informal and formal carers alike.

ii. Identifying the Context of Family Care

The foundations of family care to aged parents include family structure, interaction between a sense of obligation and implementation of normative beliefs, levels of affect and association and functional provision and intergenerational exchange of supports and services. These foundations are linked and the kinship literature demonstrates clearly that "affect" needs to be accompanied by examinations of reciprocity and exchange. Furthermore, because the provision of care is "negotiated", (and thus dependent upon the relationship between care receiver needs and caregiver ability and willingness to meet those needs), the identification of such "negotiation" (Finch and Mason, 1993) requires analysis of both care receiver and caregiver views and behaviours. Similarly, analysis of the social context of family care requires the participation of elderly care receivers because they are in possession of the most accurate information concerning the presence, ability, and willingness of friends and neighbours to provide the care and support that is needed and requested.

iii. Revealing Elderly People's Views on Kinship Obligations

Economics, biology, domesticity, and morality form the basis of intergenerational kinship solidarity (Allan, 1988). The terminology of the caregiving literature mirrors this understanding, and includes frequent reference to those normative imperatives which determine the provision of family care. A key feature of such literature has been the plethora of studies which examine the feminine specificity of parent care and the moral obligations that daughters and daughters-in-law feel to care for their frail elderly parents, (Ungerson, 1987; Meredith and Lewis, 1988; Abel, 1990; Aronson, 1990; Braithwaite, 1990). Research also identifies the degree of intergenerational and popular consensus that underpins kinship obligations to frail elderly kin and the limits of such obligations (Brody, 1981; Finch and Mason, 1990). An important information gap exists however in terms of comparing views held by care receivers with those of caregivers, and then exploring the ways in which such views are combined to operate in practice,

resulting in the organisation of family care. A related research aim here is to amplify upon the ways in which frail elderly kin can "jeopardise" the provision of family care by being too demanding or requesting inappropriate support from their family (Finch and Mason, 1990).

b. Challenging the Primary Carer Focus:

The second substantive issue to inform the scope of the study concerns the accepted wisdom that care within the family is unshared: that family care is characterised by a lone primary carer providing their caring work unassisted by other family members. This study establishes the significance of a family-wide perspective in terms of the analysis of family care. In so doing, it provides a critique of the "methodological individualism"[1] which characterises much of the caregiving literature and examines the ways in which different family members are implicated in the care of their elderly kin.

The rationale for challenging the primary carers focus in caregiving research is rooted in the mechanisms which characterise intergenerational relations. Interdependence is an important characteristic of the ways in which a family functions (Allan, 1988), and when an elderly relative requires care from other family members, each family member will, to a lesser or greater degree, be affected (Brody et al., 1989). Of course, this does not mean that every family member will provide practical assistance to their elderly relative, but rather that internal relationships will change because the pre-existing familial homeostasis will have changed also (Brody, 1985).

Furthermore, studies of kinship obligation between adult children and their aged parents suggest that it is not normative imperatives which are gender-specific, but rather their application. This suggests that kinship obligations are permissive rather

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[1] A term used by the Canadian Victor Marshall (1981) in his critique of social gerontological research which is limited to an investigation of one person's perspective on the processes which underlie, and interactions which characterise, the dynamics of relationships.

then binding, abstract rather than defined, and ambiguous rather than systematic (Firth et al., 1970). Finch therefore argues that although filial obligations to elderly kin comprise normative and affective components, they only determine the "ground-rules" (Finch, 1987). Of course, Finch and Mason go on to identify four "procedural rules" in the determination of filial obligations to elderly kin which stress the roles of joint decision-making, practicality, fairness, and quality of prior relationships in determining who does what for a frail elderly relative (Finch and Mason, 1990, p169-72). Although research in this area remains in its infancy, such conclusions suggest that the ways in which families put into practice their views on kinship obligations to elderly kin depend upon the input of more than one person: it involves the family unit as a whole.

Finally, research results illustrate that the provision of supports to elderly kin precedes, although intensifies with, the development of functional impairment (Walker and Pratt, 1992). Thus there exists the thesis that caregiving to elderly kin represents the "intensification of a pre-existing pattern of aid-giving that is evident in female intergenerational relationships" (ibid., p3). Such a conclusion reinforces the necessity of disaggregating the "caring process" and widening the analytical lens to include "aid-giving" activities undertaken by family members effectively treated as non-carers by way of exclusion from analysis.

Conceptually therefore, distinctions need to be made between "helpers" and "carers", with the former group also being seen as a legitimate focus of attention in caregiving research (Arber and Ginn, 1990, p439).

Geographically Proximate Siblings and Research Aims

Establishing whether and how children living in close proximity to a frail aged parent avoid caregiving responsibility for a frail elderly parent furthers understanding of the familial division of labour, as well as the status attribution and the operation of distributive justice within the family. Thus the major focus

here is establishing the contribution of proximate siblings to the provision of all filial care received by the elderly parent, and primary carers' reactions to that care.

i. The Provision of Aid-Giving to Elderly Kin

Arber and Ginn assert that families contain carers and helpers in terms of looking after elderly relatives, and explain the differential input of both groups according to five criteria: timeliness; indispensability; responsibility and organisation; emotional care; and severity and nature of dependency (Arber and Ginn, 1990, p439). The research issue here therefore is identification of any help that a proximate sibling provides in caring for an aged parent. The aim is to reveal whether and how geographically proximate sisters or brothers limit the levels and types of help they provide, and to examine the extent to which their aid supplements the efforts of the primary filial carer.

ii. Geographically Proximate Siblings and Kinship Obligations

A further research aim is to explore the moral responsibility for parental care that primary carers attribute to their geographically proximate siblings. Very little is known about this area of intergenerational normative support, with the notable exception of the Family Obligations Survey conducted by Finch and Mason. Rather, there is only a general impression that those family members who are little involved with the care of elderly kin do not feel guilty or anxious about the level of their involvement, (Allan, 1988, p258), while those children who are primarily involved are bitter about the lack of sibling support they receive (Brody et al., 1989). The research objective therefore is to examine primary carers' identification and reaction to the support their siblings provide their elderly parents and to examine whether primary carers explain any differences in the levels of filial care in terms of differences in perceived normative obligations.

c. Interaction Between Family Caregiving and the Provision of Home Care Services

Since publication of the Barclay Report in 1982 which endorsed the "enabling" role of social services departments, the relationship between the delivery of domiciliary services and family care has been of considerable interest to policy makers and academics alike. Despite such interest however, interactions between the two sectors in the provision of care remain characterised by confusion and ignorance.

Recognition of the fact that family care, and its encouragement, is the fulcrum of community care policy, and an increasing awareness of the costs and burdens borne by carers, helps to focus attention on the impact of formal services upon family carers and their usefulness in maintaining and improving that family care (Twigg et al., 1990). Indeed, family carers are considered by some to comprise a "moral category" which social care agencies should target in their organisation and allocation of services (ibid., p5). Policy documents and academic analysis are generally underpinned by a consensus which stresses the desirability of interaction between families and formal services in the provision of assistance for frail elderly people. Such prescription for partnership however lacks any accompanying description.

The second major theme of the study therefore is to address the ways in which family care interacts with domiciliary services. The level of analysis is that of the site of delivery of care and the opinions of both elderly care receivers and their filial carers are sought here.

Family Care and Home Care Services: Research Objectives

More specifically, this research aim comprises four main objectives: to identify the antecedents of home care service delivery; to examine the types, levels, and functions of home care services; to explore the reactions of care receivers and caregivers to the adequacy and quality of home care services; and to identify any interaction effects between the provision of home care services and the organisation of family care.

i. The Antecedents to Service Delivery

The objective here is to reveal the circumstances under which formal services are contacted, by whom and why. Specific issues concern the disposition of elderly people and their family carer(s) towards the receipt of home care services, and whether the receipt of formal services reflects the preferences, as well as the needs, of either (or both) the elderly person and the family carer(s). The identity of the person who made the referral to the Social Work Department is also relevant, again for the aim of revealing whether elderly people and/or their family carer(s) are proactive in the quest for formal assistance. The reasons given for the need for home care services is an important area of investigation; reasons such as a health crisis on the part of the care receiver, a gradual inability of the caregiver to maintain levels of care, and the prevention of institutionalisation, are all relevant in the attempt to identify similarities and disparities between the accounts of care receivers and caregivers of the rationale for the intervention of formal services.

ii. The Types and Levels of Services Received

This research objective also looks at types and levels of home care services received, and the nature of those services according to activities of daily living and instrumental activities of daily living. Furthermore, the stability of these services is examined and the impact of reassessment identified.

iii. The Adequacy and Quality of Home Care Services

Elderly care receivers and their filial carers are asked to describe their experiences of the home care services received. Included here is an overview of the tasks each service fulfils and an examination of the ways in which elderly care receivers and/or filial carers participate in the determination and management of these tasks. Elderly respondents also identify the positive and negative aspects of their receipt of home care services. Most important here however is the assessment by care receivers and filial carers whether the home care services provided meet their respective sets of needs and preferences, and whether there is any evidence of under-servicing, over-servicing, or mis-servicing of these services.

iv. Interaction Between the Provision of Home Care Services and the Organisation of Family Care

The objective here is to investigate how contemporary patterns of care are delivered by formal and family carers, and how they "interweave" according to activities of daily living and instrumental activities of daily living. Also of interest is examination of the ways in which interaction effects between the two sectors develop and change over time. For instance, is there any evidence to support the notion that interaction effects evolve over time; from supplementation, to complementarity, to substitution, to complete independence? Furthermore, does the nature of the interaction vary according to the developing quality of relationship between elderly care receivers, their family carer(s) and home care workers.

d. Research Design

The study combined both social survey techniques and qualitative interviews. The aim was to optimise the benefits offered by both approaches: to describe prevailing patterns of care from filial and formal sources; to examine the meanings attached to those patterns as explained by both care receivers and carers; and to assess the intra and inter-sectoral interactions they describe. The design involved a two stage sampling strategy, both involving face to face interviews. Stage one comprised a survey of elderly people in receipt of domiciliary services from the local Social Work Department while stage two consisted of interviews with primary filial carers. Stage one interviews involved the application of a structured questionnaire. Stage two interviews were more qualitative in design although they repeated several of the questions asked of elderly participants in order to facilitate comparability.

e. Plan of the Thesis

Finally here, it might be useful for the reader to have a general view of the way in which this thesis is organised. The thesis is divided into another nine chapters, eight of which deal with specific research objectives. These chapters review the relevant literature, present study data and discuss conclusions. The intention is that they can be read largely as discrete and substantive pieces of work. The final chapter provides a summary of the main discussions which have characterised the thesis and a synthesis of the main conclusions.

More specifically, chapter two provides an overview of the methodological and conceptual considerations which defined the research design. This chapter is very much a "hands on" description of how the study was developed.

Chapter three sets is the first of four chapters which provide an overview of the dynamics of filial care and sets out the significance of the **receipt** of care as a substantive topic for the caregiving literature. It also provides a profile of the

elderly participants who provided the information upon which the bulk of this thesis is based and charts their "objective" need for practical support from others.

Chapter four explores the subjective definitions and measurements elderly participants attached to their care needs. It identifies their carers and charts any gaps in the scope and extent of assistance they receive. In particular, the chapter provides a detailed breakdown of family carers and conducts a preliminary examination of differences in carer activity according to filial gender.

This latter theme is taken up in greater detail in chapter five which explores the basis of family care via reference to the structural, affectual and attitudinal characteristics and values which form the foundations and motives for filial care to elderly parents.

Finally with regard to the dynamics of filial care, chapter six comprises a critique of the orthodoxy which promotes "unshared care" as the predominant characteristic of family care. It identifies secondary family carers and investigates the limits to shared care as they pertain to adult children.

Chapter seven is the first of three chapters devoted to the relationship between filial care and domiciliary services and addresses elderly participants' and filial carers' experiences of domiciliary services with specific regard to referral process, adequacy of service levels and service management.

Chapter eight addresses the practical interface between filial care and domiciliary care. It provides a critique of the conceptual frameworks applied to the relationship between the two systems of support and then explores and contrasts care receivers' and carers' direct experiences and understandings of this relationship.

Chapter nine on the other hand argues for the systematic inclusion of care receivers' experiences in the conceptualisation of care and explores the meanings and significance attached to formal care and filial care by the two respondent groups.

Chapter ten provides the synthesis of the main conclusions.

In total therefore, this research seeks to understand and explain the dynamics of filial care to elderly people and its links with official welfare. And while it is hoped that the research furthers understanding in both these areas, the strategy employed is one which often takes the reader "back to basics" and a re-evaluation of the orthodoxy which underpins much of the care literature.

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THE DESIGN OF THE STUDY

> Methodology is viewed as the interface between methodic practice, substantive theory and epistemological underpinnings.
> Harvey, 1990 p1

Introduction

The fundamental tenet of any research design is that it results from the research problem. The design question posed by this study was how to examine the experiences of elderly care receivers and their filial carers in describing and explaining the dynamics of family care to elderly kin and its links with official welfare. The research deals with personal experiences in their social contexts and its design had to be capable of relating individual experiences and realities into wider social processes.

This chapter describes how my study was conceptualised, designed and executed and describes the choices I was faced with and the decisions I made. These choices and decisions are linked with the philosophical debate which characterises social science methodology although I have tried to avoid making too many purblind statements about epistemology. This chapter concentrates upon the methodological choices presented by my research objectives and how those objectives effectively established the basis of my research design. This pragmatic approach reflects a conviction that it is the application of the philosophical debate about epistemology rather than the debate itself which is most useful in explaining and justifying the execution of a piece of research.

Acknowledging the Intellectual Roots of Social Science Research

The problem of "practice" is central to the intellectual foundations of the social sciences and philosophical debate about research practice has been both epistemological, (i.e., concerned with the source, nature and limits of knowledge), and ontological, (i.e., concerned with the basis and assumptions upon which notions of reality are based). This philosophical debate has been integral to methodological development within the social sciences and, as such, requires acknowledgement by research practitioners and explanation of how it informed the development of their own research.

The range of the philosophical polemic is most readily revealed by two paradigms which compete to answer the apparently simple question about the constituents of social science research methods. These are, of course, the positivist and interpretive schools whose renowned exclusivity is exacerbated by their historical alliance with different disciplines, different fields of study and different research questions. Positivism is founded upon the principle that the proper rationale for social change relies upon impartial and objective assessments of societal performance; there is little room for, and no formal acknowledgement of, politics in the positivist research campaign. Rather, positivist epistemology determines that the measure of excellence in social science research is the delivery of internal and external validity; studies which are amenable to replication , "powerful" in terms of statistical confidence and generalisable to other samples and populations. Characteristic, if not a caricature, of such research is the central position occupied by the concept of "objectivity". Demonstrable "objectivity" is both the purpose of such research as well as its method; it defines the art and fashions the researcher's tools. Akin to their cousins in the natural science research communities therefore, positivist research practitioners within social science faculties seek to identify and prove the "facts" of social phenomena; facts which are deliberately set apart from the subjective states of individuals, or groups of individuals.

In direct contrast, research conducted from the interpretive perspective is underpinned by the Weberian goal of "verstehen"[1]: understanding the subjective motives and beliefs behind people's actions. The interpretive perspective places emphasis upon the values which define a research problem and thereby engages with the "politics" of research in terms of the values which underpin the research agenda. The measure of excellence here is denoted by the ability to capture the complexity of meanings research participants attach to their experiences, needs, observations and preferences and for the research to be as "natural" as possible. Interpretivists reject the positivist concern with "observable facts" and question the suitability of the philosophy and techniques of the natural sciences for social science research. Philosophically, the roots of the interpretive paradigm lie in phenomenology and symbolic interactionism: reaching understanding from the perspective of those being studied and to give that understanding its correct context. Simply stated therefore, the important interpretive "reality" is what people perceive it to be, regardless of randomisation and statistical "validity" .

Proponents of the interpretive paradigm partly base their philosophical stance on the argument that the advocacy and construction of scientific "objectivity" within positivist social science is little more than an oxymoron: the positivistic claim to objectivity is partial, value-laden and thereby inherently flawed. A particularly effective version of this argument is captured by feminist research theory and practice whose cogent critique of the positivist paradigm poses significant questions about the neutrality of social science research in terms of agenda creation and methodological execution. For instance, Margrit Eichler's seminal work demonstrates that certain "malestream" assumptions are ubiquitous throughout social science research. She conducts a detailed examination of these assumptions and codifies them according to "primary" (androcentrism, over-generalisation, gender insensitivity, and the use of double standards), and "derived" (sex appropriateness, familism and sexual dichotomy), types (Eichler,

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[1] Abel, T. (1948): provides the exemplary model whereby verstehen is associated with inductive theorising and not hypothesis testing because its major concern is with intervening processes which provide subjective meaning to actions, opinions and motives.

1988). As Eichler herself argues, the major value of her codification rests with the way in which she exposes the multidimensional nature of sexist research practice rather than with the precise configurations of the categories themselves. By demonstrating so clearly that sexist assumptions and biases underpin the majority of research conducted under the banner of social "science", Eichler, and other feminist writers like her, put paid to the positivist claim of objectivity. And while a major outcome of such feminist critique of positivist social science has been to expose the previously unacknowledged "androcentricity" of research agendas, the major research outputs have been the development of new research agendas and remodelled research tools which are not alien or threatening to the ways in which women recognise and explain their world. Such outputs are highly significant. Within the field of social work research for example, it has been argued that feminist theory and research has:

> ...identified and explored the impact of gendered assumptions underlying the identification of need and the distribution of resources....Above all, it has encouraged and informed new - less threatening - ways of working with those women and girls who comprise the majority of social work's clients.
> Lupton, 1990 p20

As this quotation suggests therefore, epistemological debate within the social sciences is not some rarefied activity designed simply to test the intellectual and semantic skills of academics. It sets out fundamental principles of practice from which all other research design and methodological issues, including ethics, originate.

Grossly stated, the interpretive paradigm is often associated with qualitative research methods, while positivist goals are more often pursued via quantitative methods. Each of these "itative" headings however is underlain by a wide range of research designs. Different qualitative research designs include: the case study which makes no effort to control the variables under examination (Campbell and Stanley, 1963; Yin, 1993); the analytic inductive design which seeks to develop and test theory (Denzin, 1970); grounded theory or constant comparative design

(Corbin and Strauss 1990; Glaser 1992, 1993; Strauss and Corbin 1990); and ethnography and phenomenology (Denzin and Lincoln, 1994).

The equivalent listing of quantitative research designs includes: social surveys; controlled randomised experiments; quasi-experiments; and longitudinal or time series studies [1]. Inherent to the quantitative research design is a (quasi) randomisation in the recruitment of research participants: a process whereby internal validity, and thus inferential power, is best assured (Fisher, 1935).

The Search for Complementarity Between the Paradigms

Historically of course, the positivist and interpretive paradigms have been regarded as philosophically antithetical and technically divergent and many researchers have pursued separatist methodological routes when developing and justifying research designs (e.g., Becker, 1970; Campbell and Stanley, 1963; Spradley, 1980). A major problem with such exclusivity however is that when research methods become too highly valued by their practitioners, they can become ends in themselves. And, instead of research issues providing the catalyst for design and methodological decisions, researchers run the risk of allowing research methods to determine the research agenda. It is hardly surprising therefore that philosophical debate within the social sciences also highlights the importance of searching for complementarity between the analytic induction and hypothetico-deduction schools of thought (Fielding and Fielding, 1986, p10-11). Indeed, if the raison d'être of the "sociological imagination" is to understand the intersection between micro and macro, self and social structure (Mills, 1959), then finding ways in which data can be combined so that the researcher gains greater understanding of how individuals are simultaneously prone to social and subjective forces becomes the essential task.

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[1] Catherine Hakim's 1987 book "Research Design: Strategies and Choices in the Design of Social Research" provides an excellent overview of the strengths and weaknesses of eight types of study including the ad hoc social survey, regular and continuous social surveys, longitudinal studies and experimental social research.

This groundswell of opinion which rejects the superiority of any exclusive or "purist" deployment of positivist and interpretist traditions is based, in part, on the observation that aspects of both paradigms are deployed at different stages of the overall research process. For instance, social surveys often base the categories of investigation and analysis upon the results of qualitative work undertaken during pilot phases which reveal appropriate and relevant constructs and indicators. Similarly, quantitative concerns often underlie the analysis of data produced in qualitative studies and methods such as discourse analysis are predicated on locating and enumerating similarities and differences in qualitative data. Both quantitative and qualitative research are therefore based on the notion of indicators and an increasingly common argument is that "good" social research demands a range of methods belonging to both paradigms. Research techniques which are combined to bridge the philosophical divide within the social sciences have been given a number of names including methodological triangulation (Fielding and Fielding, 1986), multimethod research (Brewer and Hunter, 1989), and combined-methods research (Marshall, 1981)[1]. To complicate matters further, there are four types of research "triangulation": data, researcher, theoretical and methodological.

The rationale for developing such triangulated research designs is comprehensively and convincingly stated by Denzin:

> ...by combining multiple observers, theories, methods and data sources, sociology can hope to overcome the intrinsic bias that comes from single-method, single-observer, single-theory studies.
> Denzin, 1970, p313.

In other words, the major strength of "combined-methods" research designs concerns confidence: if diverse types of data and different sources of data reveal similar characteristics and support the same conclusions, then confidence concerning those conclusions is strengthened (Fielding and Fielding 1986, p24). This is because:

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[1] I use the term triangulation through this chapter in my descriptions of my own study.

> A diversity of imperfection allows us to combine methods that not only gain their individual strengths but also to compensate for their particular faults and limitations. The multimethod approach is largely built upon this insight. Its fundamental strategy is to attack a research problem with an arsenal of methods that have overlapping weaknesses in addition to their complementary strengths.
> Brewer and Hunter, 1989, p17.

Succinctly therefore, researchers defend their use of triangulation in terms of mitigating the inherent weakness of single method research design: for instance, qualitative data can provide an important cross-check of quantitative data. More pragmatically however, funds for social science research are heavily dependent upon the commissioning activities of Government and social care organisations. A significant reason for promoting triangulated research designs concerns the politics of research in applied settings. Martin Bulmer listed five obstacles to the use of social science by policy-makers: endemic empiricism; the commitment to generalist rather than specialist civil servants; assigned bureaucratic marginality; the politicisation and lack of professionalism of social science; and the policy-making process itself (Bulmer, 1983). Policy-makers rely on "facts" and the onus remains on " quantifiable and replicatable [*sic*] indicators of effectiveness or performance" (Lupton, 1990). Indeed, it may even be that the policy process is inimical to the use of qualitative research methods even though they offer a unique contribution to applied decision-making. Not only are qualitative methods more amenable to the involvement of policy-makers in the research process, such involvement is often a purposeful feature of the qualitative research design. The development of "sensitising concepts" (Diesing, 1972), is a good case in point here; such concepts reflect policy-maker concerns and priorities and are used to organise the analysis of concepts and categories as revealed by research participants.

Of course, triangulated research methods are not without their critics. Indeed, even proponents admit that multiple data sources and types incorporate a multiplicity of possible data error and thus that:

> ...triangulation...is no guarantee of internal and external validity."
> Fielding and Fielding, 1986 p24

Furthermore, triangulated research designs run the risk of "throwing the baby out with the bathwater". Ethnographic studies provide "hard" data of their own: they are not merely an appetiser on the social survey menu but a unique and substantial "main course" option. Similarly, social surveys are not simply a unique form of data collection but generally the optimal mechanism for testing data reliability and generating causal inferences (e.g., de Vaus, 1986).

Such criticisms aside however, there is a fair degree of acceptance that surveys should be used for inductive theorising and that any potential for this is enhanced by collecting qualitative as well as quantitative data during survey interviews. Open-ended questions asked during survey interviews are an efficient way of obtaining preliminary qualitative data from large numbers of people (Connidis, 1983) and may suggest new areas for future investigation. Furthermore, such responses may facilitate cross-reference with, and improve interpretation of, quantitative findings. Such confidence in the ability of survey research to accommodate qualitative methods is, of course, founded on a rejection of interpretive methodological orthodoxy which states that qualitative data can only be produced after lengthy and consistent, emotional and intellectual, engagement with research participants (Finch, 1986). Rather, this confidence is representative of the "market research style" of qualitative methods (ibid). But while the use of the open-ended question in survey questionnaires is hardly revolutionary or innovative, the calibre of qualitative data produced by such questions frequently remains unexplored while their application is limited to an amplification of responses obtained from close-ended questions.

Of course, it is important not to under-estimate the importance of "peppering the prose": such seasoning may enliven an otherwise dull and dense text and assist in the successful communication of research results. Presentation and dissemination aside however, the key task of research based on properly triangulated designs is to maximise any joint potential for empirical deduction and theoretical induction. In so doing, triangulated research designs may produce certain difficulties for researchers, a critical one being how to manage and interpret any "divergence"

(Lever, 1981), between the results obtained from different data such as happens when responses to closed questions (which force a yes/no answer from the respondent), differ from those produced by less structured questions. Divergence begs evaluation of which responses were correct: was the respondent telling "the truth" during one response and "lies" during another? And should equal import be accorded to both responses? These questions are not easily answered and hinge on the conclusions drawn from the philosophical debate outlined above; whether one paradigm is superior to, more "valid" than, the other. It is also important to realise that there may be several reasons why the same question, asked differently, might elicit different responses: the most obvious concern interviewer effect and the propensity of respondents to provide socially acceptable answers. During interviews based on highly structured questionnaires, the interviewer controls the agenda and directs the respondent through a pre-arranged interview schedule consisting of a series of close-ended questions. This involves respondents having to choose between options which may apply with equal force or irrelevance to their own situations, provoking responses which, although "true", are "not the whole truth". During unstructured interviews in which the interviewer seeks to facilitate more natural styles of conversation and is prepared to pursue issues identified by the respondents, the explanations provided by respondents about why they answer a certain question in a certain way may be more important than the answer itself. Furthermore, respondents may reply in such a way that their responses are deliberately designed to meet certain social protocol rather than draw attention to their dissension from standards they understand to be social norms.

Despite attendant difficulty, I decided triangulation would produce the optimal design for the satisfaction of my research objectives. Basically, my study combined aspects of social survey and more qualitative techniques in the development of an optimal data profile. My triangulation involved using different sorts of data and different respondents in producing data which was amenable to standardisation yet rich in detail and individuality.

Research Design Issues

Fundamentally, the task of the research design required by this study was to provide a platform of challenge for the primary carer focus which predominates in the care literature and to base the analysis of filial care and its links with official welfare upon data provided by both filial carers and their elderly parents. First, the design needed to be able to identify and differentiate between different types of filial and other family involvement in the support of the elderly participants. Second, the research design had to be capable of explaining the provision of care within the context of the care needs of the elderly recipients. Third, the design had to be sensitive to family structural characteristics and inter-relationships. The dynamics of family care, the relationships defined and circumscribed by care needs and care abilities and willingness are as important as the usual listing of tasks performed. Fourth, the design had to address the characteristics of the total support network used by the elderly participants and be able to identify and assess the ways in which different components of that network interacted.

Collectively, these four demands identified the need for a clear conceptualisation of family care to frail elderly kin. Without clear distinctions, the care provided by a variety of family members may be obscured by the analysis of primary carers. Furthermore, the researcher can not explore how some family members are able to avoid the primary carers role while others can not. Similarly, without exploring the experiences of care receivers, the dynamics of family care are incomplete while a lack of knowledge about a family's structure, functional and emotional integration places the stability of those dynamics into question. Finally, without analysis of the ways in which formal services are mobilised, and how they operate in conjunction with or contrary to family care, prescriptions for long term care public policies are likely to be vague and ineffective.

This study combined aspects of social survey and more qualitative techniques in the development of an optimal data profile: data which was amenable to standardisation yet rich in detail and individuality. The aim was to optimise the

benefits offered by both approaches. The introductory chapter explained that identification of three substantive gaps in the care literature provided the impetus for this study: a general oversight of the experiences and preferences of elderly domiciliary service users; the predominant focus on self-defined primary family carers and exclusion of other family members in the familial care system; and a lack of understanding about the relationships between family and formal care at the site of care provision and receipt. Each of these gaps had design implications for my study. I argue at length in later chapters that the effects of not placing elderly care recipients alongside carers in the conceptualisation of family care include: their passive placement vis-à-vis carers; a partial conceptualisation of care which ignores the significance of care receipt; and the exacerbation of scenarios in which the needs of carers are pitted in direct opposition to those of care receivers. Axiomatic to the design of my study therefore was a desire to allow elderly care receivers to establish the research agenda. I wanted their descriptions, experiences and interpretations of the "care" they received from their family and elsewhere to provide the key issues.

In according central position to elderly care receivers in this way, it became increasingly apparent from my review of the literature that not only should my interviews with them precede those with carers, but also that the style of the interview I proposed to conduct was very important. Other researchers have found that although elderly respondents are more than able to answer direct, highly structured, questions, they frequently do so in roundabout and convoluted ways. Even highly structured interviews with elderly people are likely to become infused with narrative (MacPherson, Hunter and McKeganey, 1989, p15). Rather differently, the Canadian social gerontologist Victor Marshall emphasised "researcher reactivity" as the greatest practical difficulty with elderly respondents: he found them particularly prone to providing responses they thought interviewers expected and wanted to hear (Marshall, 1981 pp35-6). Consequently, he concluded that highly structured questionnaires are unsuitable for interviews conducted with elderly respondents; he argued that it was preferable to allow elderly people themselves to set the interview agenda because this will provide

more meaningful information. It is also pertinent to recall that the Kent Community Care Scheme abandoned its original, highly structured, assessment form for elderly service users in favour of one which was shorter and more flexible. This amended assessment form contained far more space for elderly service users' subjective descriptions of their abilities, needs and preferences; it attempted to strike a balance between the production of standardised data and individual case study (Challis and Davies, 1986).

In contrast to this body of opinion, however, Hoinville (1983), found that interviews with elderly people exaggerate the conflict faced by an interviewer in determining their interviewing style: it is inordinately difficult to behave as "an automaton" who refuses to influence an elderly respondent's answer because of the particular need to provide simultaneous encouragement and explanation. Isobel MacPherson and her colleagues drew an apposite conclusion here with regard to elderly respondents:

> It is almost impossible for an interviewer seeking qualitative data via semi-structured or unstructured interviews not to have some effect on responses given by the interviewee.
> MacPherson, Hunter and McKeganey 1989, p15.

In other words, interviewer effect is almost impossible to avoid during unstructured or semi-structured interviews with elderly people. Expressed in stark terms, the interviewer has to work hard to keep the elderly respondent "on track" during the interview in order to ensure that the issues and topics that comprise the research also comprise the interview agenda. If anything of course, interviewer effect is likely to be particularly pronounced when the elderly person being interviewed is physically frail: the interviewer is more likely to repeat, explain or rephrase questions simply because the respondent might have poor hearing, concentration or memory. My own interviewing experiences bore particular witness to this practical difficulty facing interviewers. Increasing physical frailty amongst elderly people is invariably accompanied by a diminution of their physical social space as they become increasingly dependent on other people to "take" them to a friend's house or to a favourite club. Many of the elderly people I

interviewed appeared lonely, or at least lacking company, and naturally welcomed the opportunity to talk. As a consequence, I found myself on more than one occasion being more directive than I had originally anticipated. I certainly did not want to give offence to my respondents, nor did I wish to rigidly control the way in which respondents provided their answers, but I realised during my pilot interviews that I could not afford to conduct too many three and a half hour interviews; I lacked the stamina even if my elderly respondents didn't. A vital design issue for the stage one interviews with elderly people therefore concerned format, especially the degree of standardisation and flexibility deliberately built into that format.

From an exaggerated positivist perspective, the term "interview" paints a picture of two people; one asking questions in a certain order and in a certain way, the other answering those questions. Once the interview schedule comes to an end, so too does the interview and the interviewer departs with little or no subsequent contact with the person they have just interviewed in terms of either feedback or verification. In other words, the research interview is characterised by a social artificiality and an imbalance of power between the main parties. By way of direct and equally exaggerated contrast, the naturalist interview encourages informants to determine the agenda and develop issues they choose. The role of the interviewer in this instance is one of facilitator and interviewer skill is partly measured in terms of motivational effect. I wanted my interviews with elderly service users to provide me with a optimal route through both these interview caricatures: I needed to be able to standardise some information across all of my interviews with the elderly respondents, but I also wanted to allow my respondents to provide me with a depth of data from which I could induce their understanding of the dynamics of family care and its interaction with domiciliary services. My interviews with elderly care receivers focused on understanding: their self-defined needs and preferences for, as well as experiences of, help from family and formal services; their conceptualisation of such assistance and its place within the dynamics of family relationships; and finally how the two sources of support interacted in either complementary or contradictory ways. All of this had to be

placed in the context of family networks, health and functional ability status and domiciliary service receipt patterns. These latter contextual measurements have been the subject of extensive research and there seemed little point in my reinventing the wheel. Fundamentally therefore, my interviews with elderly care receivers contained series of highly structured questions as well as questions designed to provide a catalyst to conversation which would aid inductive theorising.

The second substantive issue which informed the scope of this study concerns the identification and role of "secondary" carers in the familial organisation of support to frail elderly people. The understanding that care is "unshared" and that one child assumes responsibility for the care and support of a frail elderly parent provides an orthodoxy to the majority of family care studies. I wanted my research to test this assumption and in so doing, to identify and examine any divergence in experience and explanation of the distribution of adult filial care as accounted for by the elderly parents themselves and the adult child that they nominated as their main family carer[1] The elderly domiciliary service users constituted the first sampling stage because it was they who determined which adult children I would approach for stage two of the study.

The accepted wisdom when triangulating data is that the research design becomes increasingly controlled as the research progresses; a progression from analytic induction to hypothetico-deduction (Douglas, 1976). My study reversed this principle and stage one interviews with elderly care receivers were more structured than the stage two interviews with adult filial carers. I was able to do this because I was not so much interested in what these adult children did for their frail elderly parents, (a myriad of studies deal with this), as their explanations of why they did so, whether their efforts differed from those provided by any siblings as well as how their efforts related to their parent's receipt of domiciliary services. Such topics have not been the subject of such extensive research and it was therefore more appropriate to use semi-structured methods in my second stage interviews

[1] My research is based upon the elderly care receiver's identification of primary family carer.

and to allow the carers themselves to establish relevant constructs for analysis. Furthermore, I was better equipped to deal with more qualitative data in these second stage interviews because there would be fewer interviews with adult children than with elderly parents. As I explain below, adult children were only approached if they had been identified by their elderly parents as their main family carer. For instance, if the elderly parent stated that their spouse was their mainstay, adult children were not contacted even if they were providing care and assistance.

Data source triangulation was used in this study and involved using different respondents, and different types of data, to explore the same phenomenon (Hammersley and Atkinson, 1983). The research design comprised a two stage sampling strategy: stage one involved "structured" interviews with 57 elderly people in receipt of domiciliary care who lived in Scotland; stage two involved interviews with 18 adult children nominated by their elderly parents as being their main family carer . Both sets of interviews were piloted as explained below.

Facilitating a Sample

The research section of the Social Work Department of a former Regional Council in Scotland provided a sample of elderly domiciliary service users for the pilot study and the first stage sample of elderly recipients of domiciliary services. These elderly people were asked to identify the relative upon whom they most depended for support and assistance and thereby determined the filial carers interviewed in the second stage of interviewing.

The pilot study was conducted in November 1992 and comprised 16 interviews with elderly recipients of domiciliary services in a small town within the Regional Council's boundaries and five interviews with adult children identified by the elderly respondents as primary family carers. This town was excluded from the sampling frame from which the sample of elderly domiciliary service users was eventually drawn. A single local social work office covered service users living in

and around the pilot town and the Departmental research section contacted the team manager for elderly services who personally approached potential respondents about my research and requested their participation in the pilot study. Because the purpose of a pilot study is to test and refine research tools, I was not overly concerned about the way in which the team manager identified the 16 elderly service users I interviewed: the structure and content of the interview schedules I had devised, not sampling error, was the main concern at this time.

Decisions which affected the recruitment of respondents onto the first stage survey however were completely different. Originally, I had hoped that the sample could be limited to new applicants to the department, aged 65 years or older, who had started to receive home care services during the past year. This would have limited the study to people approaching, or referred to, the Department because of problems associated with ageing as opposed to individuals in receipt of domiciliary services because of illnesses or disabilities characterising earlier adult life. Furthermore, for reasons to do with an elderly service user's ability to participate as able respondents, it was hoped that the Department would, from recourse to service user records, be able to eliminate all those elderly service users with known cognitive impairment.

In the event, neither of these criteria were possible to implement. I also explored with them the possibility of stratifying the sample according to age: in particular, I wanted to concentrate my research upon those people often referred to as the "old old" (75 years and older) who are known to make most use of domiciliary services. This option also proved impossible. At the time of sampling, although the Department held a central record of all the names and addresses of service users, details concerning age, the length of service receipt, information about cognitive or physical impairment, as well as levels and types of domiciliary services delivered, were contained in files stored in the relevant local offices. And, although I managed to secure the agreement of the Department to conduct my study with their service users, I was refused access to individual case files. Furthermore, Departmental management refused permission for their own

researchers to access individual files for reasons of workload. Of course, such experiences are not that uncommon: social care organisations may be prepared to "facilitate" a student's research in terms of managing the identification of research participants, but the measure of such facilitation will be curtailed by resource limitation, (especially staff time and finances), and the relevance it accords to the proposed research in terms of its own strategic and operational planning priorities. There was sufficient interest in my study for the Department to agree to its service users being identified and asked to participate, but it attached careful limits to how much "work" it could take on as a result. In the event, the Department agreed only to furnish a listing of names and addresses of elderly domiciliary service users drawn at random from central records: sampling techniques such as stratification or probability proportionate to size would have been too time consuming.

The main focus of my discussions with the Department concerned the geographical spread of my study. The Department suggested that I limit my interviews to four small towns located in the south of the Region. Team managers in each of the towns were amenable to my research, while other research with domiciliary service users that was underway in the north and west of the Region generated concerns about "research fatigue". The geographical location of the research therefore was also determined by practical contingency.

The Department agreed to select a random sample of elderly domiciliary service users, (65 years and over), whose reference number meant that they lived in towns listed above. At the onset, I hoped to be able to achieve 60 interviews with elderly domiciliary service users. The Department's research section had experience of conducting research with elderly service users and suggested that they distribute a letter and consent form to 200 elderly service users. Copies of this letter and consent form are included in Appendix 1. The Department's

agreement to distribute such a letter was particularly important: some elderly people might have become alarmed at a stranger telephoning them and asking to see them regardless of the plausibility of the research underway.[1] Furthermore, by providing an official sanction to the research, it was hoped that the Social Work Department would avoid having to field lots of telephone enquiries from irritated respondents or their relatives complaining about bothersome researchers. The letter was something tangible that potential respondents, especially single elderly people, could show to their relatives, friends, even domiciliary care workers in order to assuage any anxiety about receiving such a request "out of the blue". It was also important that the letter from the Department name me and inform recipients of my studentship at Edinburgh University; if an elderly person agreed to participate in the study it seemed counter-productive for me then to have to telephone them, introduce myself and generate exactly the same worries about plausibility.

Table 2.1: An Overview of Elderly Service Users' Consent and Refusal to Participate

REFUSED/ INELIGIBLE	n=136	**AGREED**	n=64
Refusal	66	**Interviewed**	**57**
Deceased	18	Could get no reply at address	3
In Residential Care	15	Change of Mind	4
No Response to Letter	32		

All repies to the letter requesting participation in the study received by the research section were passed directly to me. Table 2.1 above provides a breakdown of response rates. It illustrates the accuracy of the research section's calculation of

[1] During my fieldwork, there were reports of bogus social workers trying to enter the homes of elderly people in the area on one occasion I was greeted not only by a 86 year old women but also her twenty-something grandson and middle-aged daughter.

consent rates but also reveals several surprises. The reader will recall that the names and addresses of potential participants were selected from central Departmental records of then "active" files pertaining to elderly domiciliary services users. The revelation that 18 letters were addressed to persons deceased was of obvious concern to the Department; while it might have been understandable if letters had been addressed to service users who had very recently died, several of the replies indicated that the relevant service users had died more than a year previously and the relatives who had received the letter were understandably aggrieved that Departmental records had not been amended accordingly. Departmental anxiety was also expressed over the 15 replies which revealed that the individuals named were not living "independently" in the community but in local authority residential accommodation (and indeed had been doing so, in some instances, since February 1992). Finally, five letters were posted to addresses at which the addressees were completely unknown. Such results highlight the inaccuracy and inadequacy of centrally held information concerning numbers and characteristics of elderly domiciliary service users; information which provides an important basis for strategic and operational planning. Facilitating a sample for my study therefore had the unintended effect of raising questions about some aspects of the quality of management information available to the Social Work Department.

The research section forwarded the names, addresses and, where applicable, telephone numbers of elderly people who agreed to be interviewed as they received them. This meant that I was able to make contact with these elderly people within a few days of their having replied to the letter. This was important because of the possibility of poor memory amongst my respondents and because of the necessity of phasing stage one interviews over several weeks. As revealed in Table One, the Department passed on 64 names, addresses and where relevant, telephone numbers of elderly service users who gave their permission for me to contact them and arrange an interview. In three cases I was unable to make contact with the person concerned despite going to their homes three times. Due to recent illnesses, another four elderly people who had agreed to participate changed their

minds when I contacted them in order to make an appointment. Both of these problems provide pertinent reminder that generating a sample of elderly people does not automatically guarantee an interview with each person. In the final analysis, I achieved 57 interviews with elderly service users; 35% of the original listing of potential participants excluding persons deceased, people in residential care and those living at an address not recorded on Departmental central records.

Ethical Issues

Far from being of marginal interest, the ethics of social research are pivotal to the way in which a study is conducted and individual researchers are highly likely to be presented with one or more "split-second" ethical dilemmas during the course of a study (Rees, 1991). This is because social research is, in many ways, a relationship between the researcher and the research participant and the rules which govern the way in which that relationship is enacted are inherent to the value of outcomes and outputs which arise from it. Accordingly, the "rules of engagement" which underpin this relationship stress scruples and protocol. The rulebook starts with the pursuit of "informed consent": participation must be based upon information about the intent, anticipated uses and dissemination of the research as well as an ability to refuse participation. This information should avoid research "jargon" and be accessible to the participant. Next, the researcher has a responsibility to ensure that the social, physical and psychological rights of research participants are not compromised in any way as a result of their participation. In particular, the researcher should avoid unnecessary intrusion and inconvenience and should not ask questions likely to belittle the value of a participant's beliefs or behaviour. Furthermore, researchers should respect participants' rights to confidentiality and anonymity as required by the Data Protection Act and should undertake all reasonable action necessary to maintain those rights. A minimum measure involves the removal of all identifiers on every data set but may also involve changing features of the information provided by participants. Indeed, where a researcher feels that the details of a case, even in

modified state, may still enable readers to identify individual participants, it may be that the researcher has to exclude discussion of that case.

The elderly participants in my study were, by definition, physically frail and I had to be careful not to over-tax them. I also had to be sensitive to the fact that the interview dealt with delicate matters concerning the support they received from their family, their experiences of that support (some of which might be negative), and their explanations about why certain children did not do perhaps as much as the elderly participants would have wished. Finally, I would be asking these elderly people to furnish the names, addresses and telephone numbers of their adult children whom I could question in my second round of interviews. Consequently, I was very clear that I had certain ethical responsibilities towards these elderly people. Although they had provided their written consent to participating in the study, I provided a brief reminder of the purpose of the research when arranging the time of the interview and double-checked that they still agreed to participate. As mentioned above, this resulted in four elderly people saying that they now preferred not to take part. Before starting the interview I told the participants that I was not, and never had been, an employee of the Social Work Department but that I was a student at Edinburgh University. I assured them that I would not be passing on any information to the Department except in the form of a final report and I stressed that this report would not name any individual participant. If asked to elaborate here, I explained that I would change certain features of examples I might discuss in the final report to protect anonymity. Finally, I undertook not to reveal their responses to any member of their family, with the obvious exceptions when they had asked a relative to be present during the interview.

Burgess reminds his reader that ethical statements can only provide a framework for research and that they cannot always provide an answer to ethical problems that arise in the field (Burgess, 1984, p207). On a similar vein, Cassell and Wax describe the process of "ethical reflection" in which researchers continually grapple with ethical issues as they arise in the field (Cassell and Wax, 1980). A

conclusion common to both these works is that even the most detailed code of ethics is unlikely to cover all ethical issues; rather, researchers have to determine their reactions to many ethical issues as and when they occur during fieldwork.

During my fieldwork, it was not so much other family members knowing what had been said which caused concern for elderly participants but any deleterious effect of their responses on future levels of domiciliary services. Some elderly participants for instance were worried that any complaints they made about domiciliary workers would be related back to Departmental managers and cause trouble for those workers. There was one incident when a participant described how a "home help" (the term "home care" was rarely used by service users), lied on their time sheet, securing the effective collusion of the participant in so doing because they felt unable to refuse to sign the sheet. Upon further discussion, it came out that this home help sometimes did not appear for two weeks or more and thus that the number of home care hours provided was significantly below the official allocation. In one of the "split-second" decisions that researchers need to make in such circumstances, I asked the respondent whether they wanted me to do anything; I stated that I was quite prepared to tell someone from the Department if they so wished. The participant asked me not to inform the Department and I didn't even though I was concerned that this respondent was being exploited in this way. More generally however, I simply did the best I could in terms of reassuring participants that their responses were strictly confidential and would not be passed by me to the Department.

By way of direct contrast however, several participants requested that I did pass on personal details to the Department. For the mainpart, such requests were connected either with their expressed need for more information about community care services available to them or with their dissatisfaction with the level of a particular services they were already receiving. When a participant asked me to do this, I contacted a particular team manager who agreed to deal with or pass on the request as appropriate.

I was equally clear about my responsibilities towards the filial carers who participated in stage two of the study. Again, the sensitivity of many of the questions meant that I had to be very clear about ethical standards, primarily in terms of informed consent and my efforts at maintaining confidentiality between the information their parents had provided previously and the information they provided. It is important to note here that I was referred to these carers by their parents (see section below). Carers were thus aware that I had spoken at length to their parents about the family and formal care they received and their experiences of each source of support: I had to make it very clear to them that I could not divulge the contents of my interviews with parents because of the assurances of confidentiality I had previously given. In the event, only two carers asked me to tell them what their parents had said in response to certain questions: in both cases I couched my refusal to do so in terms of confidentiality and by stressing that I was particularly interested in whether there was any difference between the experiences and understanding of elderly parents receiving support and their adult children who were providing that response.

The greatest ethical dilemma I faced during my research arose during my interviews with carers. Thus one carer recalled an incident which involved them making a physical attack upon their elderly parent; they had struck their parent "once or twice" across the upper body. Furthermore, the carer admitted that their relationship with their elderly parent had deteriorated to such an extent that they were convinced it would happen again. The carer became distressed when telling me about the incident and we spent a long time discussing why it might have happened, how the carer felt afterwards, why it might happen again and what could be done to prevent it from happening again. During this conversation, I explained to the carer that it was not my role to make judgements but that I was concerned about what I was being told, both for the physical safety of the parent and for the well-being of the carer who was clearly distraught about what had happened. The carer stated that they either needed more support from formal sources or that their parent had to be taken into residential care. We both agreed that the immediate course of action was for the carer to discuss what had happened

with the key social worker. I undertook to check back that the carer had done so and when I did this, the carer informed me that another case conference was being organised. As a result of that conference, the carer later told me that their parent was going to be taken into residential care and that they had begun to look for suitable premises. I never contacted the key social worker myself on this occasion and have no way to corroborate the carer's subsequent explanation of events. In retrospect, perhaps I should have done so; I remain unsure. The carer had been so open during her interview with me that I took it to be a cry for help. I had not witnessed the event itself and I felt that the carer needed the opportunity to settle the difficulties personally.

Finally here, in terms of my obligation to the Social Work Department, it was agreed at the outset that I would provide them with a copy of the final report and present a seminar or some other form of verbal presentation if they so wished at the time of completion. It was agreed that they would not receive any copies of data tapes, even with identifiers removed, and that I would change features of individual cases in my final report if I felt that my presentation of findings would compromise participant anonymity. For its part, the Department wanted confirmation that I was not attempting to conduct any covert evaluation of domiciliary services; if that was the case they would not facilitate access to service users. I was, and remain, very clear that this study is not an exercise in programme evaluation: my research is about the dynamics of filial care for elderly parents and its linking with official domiciliary services. That is not to say of course that this report contains no "evaluative" commentary; but rather that such commentary fits into a wider analysis of elderly service users' and filial carers' description of their experiences of family care and domiciliary care rather than any structured analysis of the efficiency and effectiveness of the processes and outcomes of domiciliary care.

Stage One Interviews: A Survey of Elderly Domiciliary Service Users

A number of considerations informed the format of the stage one interviews with elderly domiciliary service users. The first concerned the ability of a functionally frail group of people to sustain a lengthy interview. Because respondents were already in receipt of domiciliary services, it was likely that they would demonstrate varying degrees of frailty, poor memory, deafness and mild confusion. Furthermore, they might be in pain from chronic ailments such as arthritis. The timing of the interview was very important: it could be neither too lengthy nor too complicated. While it certainly does not follow that all elderly people are incapable of maintaining concentration for long periods of time, because my respondents were certain to have some degree of physical frailty, I decided to limit the interviews to forty five minutes.

During my pilot interviews however, I found that even very frail elderly people welcomed the opportunity to talk about two issues certain to provoke the majority of us into discussion, especially when anonymity is guaranteed: ourselves and our families. Even though I had not intended the interviews to last much beyond 45 minutes, in reality I rarely completed an interview in under one and a half hours because of the elderly participants' willingness to, indeed insistence upon, providing me with the fullest possible overview of their family lives. Despite the highly structured format of the majority of the questions I asked, the reality of my interviews with elderly service users was that they were far more conversational than I had originally anticipated. A frequent occurrence was that a particular question prompted the elderly participant to elaborate upon some tale that effectively provided the answer to another question which arose later in the interview schedule. An example here concerns responses to the question about long-standing illnesses or disabilities: several respondents not only provided considerable detail about their state of health and peculiar ailments but also used this as a platform for description of what assistance they required as a result. Another example concerns my questions about family networks, (including geographical proximity and an overview of the emotional inter-dependency),

which prompted many respondents to embark upon explanations of why it was that certain adult children did, or did not, provide certain forms of support and assistance.

My design intent here was to provide data about elderly people's experiences of receiving care from both family and formal sources which would be amenable to standardisation and, as such, could be used to challenge the orthodoxy upon which the social policy conceptualisation of care is based: the carer perspective. In actual event, as I have just described, the "quality" of the data I obtained from elderly care receivers far exceeded my expectations; the interviews were far more semi-structured in practice that had been anticipated in pre-pilot planning. With the wisdom that only hindsight bestows, I remain convinced that the application of a structured instrument during my interviews with elderly people was the optimal research strategy to deploy: I knew from my pilot interviews that I could expect to obtain standardised data which would provide the platform for the empirical challenge I wished to pursue while also gaining access to data which would allow for the possibility of inductive theorising.

I perhaps should explain here that three "interviews" with elderly participants were done by proxy with a wife, a daughter and a son. For the proxy interviews conducted with the wife and daughter, the elderly respondents suffered from dementia and were unable to participate themselves. The interview conducted with the son was done so because his elderly parent was completely deaf. In each of these three proxy interviews, I only asked factual questions and omitted those designed to test attitudes, preferences or experiences.

Appendix Two comprises a copy of the interview schedule used with elderly participants. Subsequent chapters explain the precise content of different sections of the interviews but it might be helpful to provide a brief overview of the topics examined during these interviews here. The interview began with questions on the background characteristics of the elderly respondents including: age; marital status; identity of other household members; and an overview of their family

network, (for their adult children, this included their geographical propinquity, level of different forms of contact, economic status and age of children). Next, I went on to explore their health status and to measure their level of functional independence according to 13 activities of daily living and instrumental activities of daily living. The interview then explored what help the elderly participant received, if any, the adequacy of that help, and the identity of both a "main" helper and "other" helper for each of the 13 tasks. The next series of questions allowed the elderly participants to explain the parameters of family support they received and their experiences of that support. These questions were supplemented by a brief examination of three aspects of intergenerational solidarity between elderly parents and their adult children: functional; affectual and consensual. Elderly participants were also asked to describe and explain their receipt of domiciliary services and to measure the adequacy of the services they received . They were also asked to identify any interaction between these domiciliary and the support they received from their family. Finally, the elderly participants' attitudes towards receiving domiciliary services were examined.

As such, this interview schedule was both broad and ambitious. And, although much research has already measured elderly service users' functional ability, health status and levels of service delivery, I was forced into having to repeat these topics during my interviews in order to provide the necessary context to my investigation into the dynamics of family care and its links with official welfare.

Stage Two Interviews: Adult Filial Carers

The 18 filial carers who provided information during stage two of the research were identified during stage one. I asked the elderly participants to nominate their main family carer. If this carer was an adult child who lived in the area, I then asked the elderly participants for their permission to contact this son or daughter. If they stated that they had no objection to my doing so, I asked them for their son or daughter's name, telephone number and address. I also asked the elderly person to mention to their son or daughter that I would be making contact during the next

two weeks. For the three proxy interviews mentioned above, the wife stated that she was her husband's main family carer and thus it was inappropriate to contact any adult child for participation in stage two. The daughter and son who provided the other proxy interviews mentioned above stated that they were their parents' primary family carers. I therefore asked them directly whether or not they would be prepared to be interviewed again and they both agreed and were interviewed at later dates. It should also be noted that several of the filial carers were co-resident with their elderly parents. When this happened, and because these children had all been nominated by their parents as main family carer, requests for participation in the study were made there and then.

The interviews with the filial carers were more semi-structured in design although certain aspects of the schedule were repeated ad verbatim in order to facilitate direct comparison between the two respondent groups. This included the series of questions on consensual and affectual solidarity. In general terms, each interview lasted an average of one hour and twenty minutes (slightly shorter than the interviews with elderly parents), and were equally as conversational as the stage one interviews.

Appendix Three comprises a copy of the interview schedule conducted with filial carers. Again, subsequent chapters provide the detail for each of the topics investigated. By way of introduction here however it might be useful to simply list the major areas of discussion. The interviews began with some investigation of the carers' own family and employment status. Next, they were asked about their wider family networks including their levels of contact with, and emotional closeness to, their siblings and parents. They were asked to describe and explain the care they provided to their elderly parents and to identify the positive and negative aspects of their caregiving efforts. They were also questioned about the contributions to the care of their elderly parents provided by any of their siblings, and were asked to describe and explain their reactions to such sibling contribution. The interview then moved towards an examination of their experiences of, and responses to, the domiciliary services received by their elderly parents. Notably

here, carers were asked a series of questions designed to classify any interaction that they identified between the family care and domiciliary care including an absolute evaluation of various aspects of caring contribution provided directly by themselves and by domiciliary and community care services. Finally, the interview concluded with a repetition of the battery of consensual solidarity questions asked of elderly parents designed to test attitudes towards the normative responsibility of adult children to elderly parents.

Data Analysis

A note of explanation is also required about how the data was analysed. The data produced by both sets of interviews were analysed in two ways. First, all of the 57 stage one interviews were analysed with SPSSPC. This package is primarily designed for rectangular, rather than hierarchical, data sets[1], is extensively used throughout the social sciences, and thus provided an ideal package for examination of the results. Such examination took the usual form of quantitative analysis: description and measurement of association. The more qualitative data produced in response to open-ended questions during stage one interviews with elderly respondents were recorded verbatim during those interviews and then transcribed. These transcripts were then organised into common themes for each topic and I developed coding frames which categorised the variety of responses provided. These coded data were then also added to the SPSS data file. This approach to the analysis of the open-ended responses meant that I had access to two different data types for each respondent and could refer to both the original detail as well as the standardised synopsis.

Of course, my intention was that the statistical findings could be supported by a more biographical data which emphasised the specificity of each family situation. My aim was to examine differences and similarities between cases as well as to investigate characteristics, meaning and significance within cases. I wanted to

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[1] Rectangular data means that the same information is available for all cases. Hierarchical data describes the addition of sub-sets of data for particular cases. This means that each case does not contain identical data.

fashion the data in order to allow for both empirical deduction and "theoretical" induction.

Although the interviews with carers were far more semi-structured in design than those undertaken with elderly care receivers, nevertheless the approach outlined above was repeated during analysis of their data. It is important that I explain here that this decision was taken only when I had finished the preparation of the stage one data. Originally, and with the exceptions of those questions repeated verbatim during both sets of interviews, I had not intended "reducing" stage two data into more structured formats: I wanted this data to provide case study type material which would provide the necessary context and meaning to the structured data gathered during stage one interviews. I eventually did so however because in so doing I was not losing the depth and detail of my interviews with filial carers; rather I was adding another dimension which allowed me to more closely compare the data produced from both sets of interviews.

3

ESTABLISHING THE SIGNIFICANCE OF CARE RECEIPT

Introduction

Briefly and broadly stated, caregiving research has a tripartite schema which most frequently presents: *the demography of demand for care,* (which establishes need and the empirical significance of caregiving research via reference to demographic statistics and indicators of health and functional impairment); *the public policy response to that need,* (in particular the development, implementation and evaluation of community care policies); and *the dynamics* (the antecedents, experiences and consequences), of what is dispassionately termed "informal caregiving" or care by the family, neighbours and friends (e.g., Equal Opportunities Commission, 1980; Green, 1988; Lewis and Meredith, 1988; Parker, 1990; Qureshi and Walker, 1989). There now exists a deluge of data on each of these three topics as sociologists, psychologists, gerontologists, statisticians, economists, not to mention policy analysts and feminists, have focused their single and collective attention upon one of the most pressing issues of contemporary social policy: the proper and necessary care of ever increasing numbers of elderly people.

Despite the array of scholarly research in this area however, much of the caregiving literature portrays a predilection with individuals known as "primary carers", meaning that the opinions, experiences and preferences of elderly people themselves are frequently accorded exiguous attention (Arber and Ginn, 1990; Aronson, 1990):

> Elderly people have come to the fore in studies of informal care but are cast as passive recipients.
> Arber and Ginn, 1991 p265.

Indeed, researchers have generally overlooked the role of elderly people as family resources who enhance rather than detract from family life. Emphasis upon the dynamics of care provision and caregivers has resulted in a programme of research which treats elderly people as dependants and burdens; recipients not providers. Such classification is contradicted by empirical evidence which reveals that most elderly people do not suffer from physical health problems which severely impede their ability to manage their own daily affairs (Qureshi and Walker, 1989, p5 and p72). Early secondary analysis of the 1985 Office of Population Censuses and Surveys, (OPCS), Informal Carers Survey reveals that of the estimated six million carers in Britain, the largest single contribution is made by women in their early 60s (Green, 1988). Despite the very real contribution made by elderly people in terms of self sufficiency and caring for others however, the popular image which persists is that of a middle aged daughter caring for a frail elderly parent while simultaneously managing her own family and employment; the woman "in the middle" (Brody, 1981). Indeed, so pervasive is this particular image that Elaine Brody (1985) called it "normative stress" and a host of research has been dedicated, (under the "dynamics" heading above), to the examination of the costs and burdens borne by carers (Abel, 1990; Equal Opportunities Commission, 1980; Finch and Groves, 1980; Joshi, 1987; Parker, 1990, p57).

Of course, the bulk of this research is grounded in the needs and functional incapacity of elderly people. The salient point here is that such research has tended to present care receivers as two dimensional characters: the numbers of elderly people are increasing and normative societal expectations dictate that relatives, (especially female relatives), should respond to their measured and codified care needs. Very little interest has been devoted to the specificity or heterogeneity of experiences, understandings and preferences pertaining to these elderly people which result from decline in their functional independence. In other words, elderly care receivers have been accorded no "third dimension".

With the obscurity that surrounds many of the experiences of elderly care receivers in mind therefore, this chapter charts the significance of care receipt and care receivers for the research agenda which describes and explains the social, personal and economic phenomenon of "family care". By placing the elderly people at the centre of analysis, this chapter begins a process repeated throughout this thesis: an analysis of family and formal support which neither objectifies nor obscures the experiences of frail elderly care receivers.

This chapter also "introduces" the elderly people who participated in this study and charts their need for practical care in terms of functional ability. It is important to recognise here that these latter data are frequently found in studies which measure and chart elderly people's need for formal and informal support and will thus be very "familiar" to the reader. It is impossible to overlook such data however because they play a large part in defining the skeleton upon which the figure of formal and family care is modelled.

The Significance of Care Receivers

One of the principal claims made as an heuristic device throughout this thesis is that existing care research has effectively colluded with a pervasive objectification which typifies so many of society's attitudes towards older people. Such an indictment requires substantiation and rationale.

With a few notable exceptions (Evers, 1985; Qureshi and Walker, 1989; Arber and Ginn, 1990; Aronson, 1990), the experiences of those receiving care have been almost entirely overlooked in the care literature. Mitigating circumstances reflect the legitimate and understandable concern of researchers to reveal the sexist underpinnings of community care policy and to deliver a public visibility to previously invisible work conducted mainly by women in the domestic arena (Land, 1978; Finch and Groves, 1980; Baldwin and Twigg, 1991). Justification aside however, research which addresses only the dynamics of care provision produces a biased picture of the "caring process" (Morris, 1992) and acts to further

marginalise the way in which elderly people are treated within mainstream sociological theory and research (Nissel and Bonnerjea, 1982; Abel, 1987; Qureshi and Walker, 1989; Arber and Ginn, 1990). As a result, there are at least four reasons for challenging the caregiver bias within the caregiving literature.

First, research which focuses only upon the caregiver fails to present a full analysis of family care to frail elderly kin because it: does not adequately explore the operation of reciprocity within the caring relationship; pays little attention to the incidence of physical and emotional abuse in the caring relationship; cannot produce clear conclusions regarding the quality of the caring relationship; and fails to examine the extent to which disabled people are carers as well as cared for (Morris, 1992 pp35-8). In order to avoid being labelled as "oppressive and alienating" (ibid p22), the focus of caregiving research has to be caring, not carers; the study of relationships, not simply the provision and effects of instrumental support.

Research which examines intergenerational relationships (especially the incidence of reciprocity and exchange within those relationships) emphasises that, far from being highly dichotomised, the provision and receipt of care is best conceptualised in terms of changing patterns of two-way support (Qureshi and Simons, 1987). Care receivers thereby should not be treated as mute, passive and anonymous: rather, their subjective needs, interests and preferences should and must be canvassed if we are to achieve a more comprehensive understanding of the caring relationship.

Second, and following on from above, there is increasing interest in the impact of family and formal care upon the autonomy exercised by functionally impaired elderly people. At issue here is whether the receipt of long term care services in any way jeopardises the autonomy available to elderly people via paternalistic decision-making on the part of formal or family carers (Cicirelli, 1992). Such jeopardy may result from a situation whereby the carer is compelled to compromise, or even ignore, the preferred options of the elderly person as

ascertained by explicit discussion or "tacit understanding" (High and Turner, 1987). For instance, a carer may prevent an elderly person from doing something for reasons of safety; they might prefer to cook their own meals but be unable to lift hot pans from the top of the cooker.

Of course, the construct of autonomy needs dissection. Of particular importance from the elderly person's point of view is the distinction between *decisional autonomy* in which the elderly person is capable of independent decision-making, and *executional autonomy* whereby the elderly person being able to carry out their decision (Collopy, 1988). Cicirelli's thesis about paternalistic decisions adopted by carers is effected, in part, by this disjuncture between an elderly person's decisional and executional autonomy: carers' paternalistic decisions and behaviours may be seen as a response to this disjuncture provided they are concerned with the welfare of the care receiver and know which decisions and actions are most beneficial to the care receiver (Cicirelli, 1992, p27). Thus a carer is not acting paternalistically if they intervene in an elderly person's preferred course of action in order to exploit or dominate them; they are simply being exploitative (ibid., p28).

To complicate matters further, where the elderly person suffers from dementia or is so physically incapacitated that they are unable to make decisions for themselves, then the issue of surrogacy, rather than paternalism, enters the analytical framework (High, 1989). But this again implies an ethical position because the carer is substituting for the elderly person and accords the elderly person's welfare primary position over their own.

In the large majority of cases however, elderly care receivers are perfectly capable of expressing their preferences concerning the content and extent of assistance they should receive. Whether and how elderly care receivers do this, the accompanying character of relationships they have with their formal and family carers, and indeed the care elderly people actually receive in the light of their articulated and known preferences and needs, are all issues which focus research attention upon

"the caregiving dyad" and the ways in which decisions are made by two or more individuals operating in discrete, and in terms of power and role status unequal, social situation (Cicirelli, 1992 p50-53). The relationship between care receipt and individual autonomy raises a whole host of ethical issues surrounding decision-making in the planning and delivery of long term care of the elderly. Indeed, research already suggests that family caregivers experience considerable conflict between their desire to foster and maintain the autonomy of the care receiver and their perceived need to adopt a more paternalistic style of decision making on the care receiver's behalf (e.g., Pratt, Schmall and Wright, 1987). Unfortunately, as far as my literature review has allowed, it would seem that data which address how elderly care receivers perceive, and react to, this carers' dilemma is most conspicuous by its absence.

The third reason requires slightly more introduction and concerns competing theories of ageing. Of particular pertinence are the principles and preachings of disengagement theory which, in its simplest form, and as originally envisaged by Elaine Cumming and William Henry (1961), states that ageing involves an inevitable withdrawal from productive and public life. Within this theory of disengagement, the phenomenon of retirement, for instance, is seen as inevitable and desirable; relieving the ageing individual from the pressure to maintain high levels of productivity and concurrently enabling society to benefit from the efforts of younger, presumably more energetic and better qualified, workers. Of course the empirical basis of the conclusions drawn in disengagement theory have been founding wanting for some time; indeed, a study of Britain, Denmark and the USA in the mid 1960s found little evidence to support the thesis that the activities of people decline significantly with age provided they remain healthy and have access to reasonable levels of income (Shanas et al., 1968). Caveat aside however, disengagement theory continues to resonate in economic policies which ensure that the incomes of elderly people are increasingly differentiated from (i.e. lower than), the rest of society.

The assertion that the disengagement of older people from society is desirable, necessary and inevitable belongs, of course, to the sociological school of functionalism which views the elements and members of society as functionally interdependent. Simply stated, functionalist theory stresses the inevitability of separation between older people and younger generations by pointing to the demands of industrialisation which have acted to effectively reduce the stability of the extended family in order to increase the mobility of labour. For Talcott Parsons, the consequent isolation of elderly people from their family, communities and the world of paid work, explains the development of welfare agencies and benefits devoted to them: the state acts with benevolence to compensate elderly people for the break up of the family and for their loss of earning power (Parsons, 1951).

Critics of the disengagement thesis and functionalist theory have been vociferous and effective in their denunciation of the pathological origins of ageing and the social isolation of the aged. Social gerontologists in particular maintain that old age is a socially created artefact which assigns an artificial homogeneity to huge numbers of individuals whose principal common characteristic is that they have simply reached some arbitrarily determined age at which society expects them to cease "work" (Phillipson and Walker, 1986). The main conclusion they draw therefore is that the term "old age" is value laden and problematic (Bytheway, 1990), deserving careful analysis and conceptual clarification. Social gerontologists refer to the "acquiescent functionalism" (Townsend, 1981, p18), which predominates in societal attitudes towards elderly people. This functional perspective assigns pathological origins to the myriad of difficulties faced by elderly people as a separate cohort within the population at large, and maintains that during retirement elderly people are no longer net contributors to society but net consumers, beneficiaries, of societal resource allocation. In their critique of economic and sociological theory, social gerontologists have provided empirical evidence in order to support and explain the effects of "structured dependency" experienced by elderly people. Their main argument is founded upon the tenet that the economic, social and familial dependency exemplified by elderly people is

created and maintained by the demands of capitalism. Public policy and its accompanying institutions and agencies act in collusion with such capitalist demands and act to reinforce their negative impact upon elderly people (e.g. Estes, 1991; Walker, 1980, 1982).

The structured dependency that elderly people face is thus not only limited to retirement, but affects all areas of their lives. For instance, in the same way that compulsory retirement results in a separation of elderly people from "productive" activities, so a pensions policy which facilitates the lowering of real value of incomes during retirement relative to wages and salaries acts to restrict the type and number of activities available to older people. The dependency of elderly people is also encouraged and exacerbated by the management methods found in residential care homes for elderly people. Indeed, a panoply of theoretical (Goffman, 1961) and more empirical research by sociologists such as Townsend (1957 and 1968), and especially Booth (1985), documents the detrimental effects of residential living upon elderly people in terms of improving, or even maintaining, their domestic skills and abilities.[1]

Community care policies also act to structure the dependency that elderly service users face via a lack of review of services and an approach which treats service users as passive recipients rather than partners in the delivery of services. For instance, the development and application of "dependency scales" based on activities and instrumental activities of daily living effectively focuses attention upon the nature and magnitude of functional "problems" exhibited by elderly service users because they are specifically designed to assess need and ration access to domiciliary services. Dependency scales are also commonly used within the caregiving literature in order to categorise the needs of elderly people, and to explain the patterns of care provision in the light of those needs. Dependency in

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[1] In fact, Booth's 1980 "census" of 175 homes for the elderly in North Yorkshire, Derbyshire, Nottinghamshire and Kirklees found that 42% of the elderly residents could be classified as "independent", thereby drawing attention to the very important issue of inappropriate institutional care of elderly people and the creation of an artificial dependency via restrictive routines and practices.

this case is thereby contingent upon the measurement of codified need. But, it can be argued that these dependency scales also act to "structure" care needs because they apply methods of measurement over which the person being assessed has little control, and refer to discrete areas needs which domiciliary services can address. In other words, they may ignore the "potential" for an elderly person to overcome their functional impairment via practical, financial, even moral, support and may effect a definition of need about which the person being assessed is often not consulted (see Qureshi and Walker, 1989, p179).

In terms of measuring the needs of frail elderly people therefore, and especially in terms of meeting those needs, the opinions and preferences expressed by elderly people themselves should form the principal component of the definition process. As Qureshi and Walker remind us:

> "...elderly people were regarded as the best source of information about their own needs and attitudes towards the care they might be receiving." Qureshi and Walker, 1989 p8.

Fourth and finally here, the receipt of care by functionally impaired elderly people, and the provision of care by family members is best described via reference to a "caring matrix" (Lewis and Meredith, 1988). A caring matrix focuses attention upon the variety of interrelationships and correlates in operation between different forms of informal and formal assistance. It takes its reference from *familial* (Ungerson, 1987; Qureshi and Simons, 1987; Finch and Mason, 1990), *social* (Walker, 1980; Abrams, 1980; Seed, 1990), *physical* (Walker, 1977; Phillipson et. al., 1986), and *organisationa*l environments (Challis and Chesterman, 1985; Froggatt, 1990; Barnes and Wistow, 1992).

The actual dynamics of the caring matrix provide the material provision, receipt and exchange of basic, supportive and remedial services (Equal Opportunities Commission, 1980 and 1982; Evandrou et al., 1986; Green, 1988). Such dynamics can only be understood via chronological, material, ideological and affective contexts. More important however, because a fundamental tenet of the caring

matrix approach depends upon the actions and sentiment of care provision and care receipt, the descriptions and explanations of these actions and sentiments require the inclusion of care receivers in any research design.

For instance, in terms of the chronological and material caring contexts, the composition of "caring biographies" (Lewis and Meredith, 1988), allows the researcher to chart changes in the caring relationship in terms of changing circumstances throughout the life course. Lewis and Meredith construct caring biographies with reference to these dual contexts for adult caregiving daughters, but admit that results might be distorted because the opinions of mothers, the care receivers, are not included in their analysis (ibid., p4). By ignoring the accounts of elderly people concerning the chronological and material circumstances which precede and accompany contemporary patterns of family care, caring biographies can only provide a partial catalogue of the development of caring relationships that take place between elderly people and their younger kin.

In terms of the ideological and affective contexts of the caring biography, examination of accounts provided by both caregivers and care receivers concerning their preferences and attitudes towards family care of the aged has, of course, been undertaken in seminal research by Elaine Brody (1981). Although the empirical accuracy of her "woman in the middle" thesis is now under review (e.g. Rosenthal et al., 1990; Spitze and Logan, 1990), results from her research reveal a clear divergence of opinions held by elderly women, their daughters and grand-daughters about the normative imperatives and affective antecedents which motivate the provision and receipt of family care. Finch and Mason make the important point that filial obligations and kin supports for elderly people are, in practice, "negotiated" within families, and that it is possible for elderly people to jeopardise the provision of family care by being too demanding and/or making inappropriate demands (Finch and Mason, 1990, p152). Indeed, the kinship literature in general stresses the importance of explaining inter-generational solidarity in terms of the notions of affect, reciprocity and exchange (e.g., Qureshi and Walker, 1989; Finch, 1987); all of which are essentially relational in character.

The organisation of family caregiving for elderly kin involves a two way relationship between the supply of care and the receipt of care. In order to explain the caring relationship that exists between elderly people and their younger kin therefore, the accounts of both parties to the relationship, care receivers as well as caregivers, should be sought. Both sets of views regarding the normative obligations and responsibilities families fulfil in caring for frail elderly kin are of equal import: after all, it is the interaction between the parties in terms of ways in which these views are put into practice which determines the features, character and perceived effectiveness of the actual family care provided and received.

Elderly people in receipt of formal and family care are the linchpins of this study. They not only comprise the first stage of the sampling strategy but also: establish the circumstances under which family care and home care services are received; give an indication as to their reactions to that receipt; and identify the adult children to be approached for participation in stage two of the study. This is very different to the more usual research design employed in caregiving research in which "primary carers" are self selected and where the panorama of the caring relationship is revealed from a unidirectional perspective.

An Introductory Profile of the Elderly Participants

Fifty seven (57) elderly recipients of domiciliary services living in the fieldwork area were interviewed for this study. The interviews were conducted in the respondents' own homes and comprised a structured questionnaire with responses written down verbatim. The youngest respondent was a woman of 65 and the oldest a woman of 93. Considering that all the respondents were recipients of domiciliary services organised by the local Social Work Department (SWD), it is perhaps surprising that only three interviews[2] were conducted, in effect, by proxy. Even in these three cases however, the elderly person was present throughout and

[2] Of the three cases, two elderly people were severely confused whilst the third was profoundly deaf.

the respondents (a son, daughter and wife respectively), asked them for their concurrence at several points during the interview.

In terms of the practical difficulties encountered in approaching very elderly people as research informants, I agree with the positive conclusions that Bury and Holme draw in their study of over 90 year olds:

> ...the ability to interview the very old, allowing for an inevitably higher incidence of severe memory loss, was comparable with that of interviewing younger age groups and that reliable information can be obtained.
> Bury and Holme 1991 p142.

Indeed, the practical difficulties could be anticipated in advance. Many of the respondents were deaf and questions had to be repeated and asked slowly; several respondents interrupted the interview in order to use the toilet; a few had to take medication during the interview or have a dressing replaced. All of the respondents however gave their fullest attention and provided the most detailed responses they could muster. Indeed, I did not find interviewing elderly people, many of whom could be classified as "old old", to be a problem: indeed, their frankness, enthusiasm, and hospitality made them ideal respondents.

The participants can most simply be described as: **female; "old old"; widowed; and living alone.** More than two thirds of the participants were **women (39; 68%)**, whilst just over four fifths were **aged 75 or over (46; 81%)**. Over three quarters **(43; 75%) were widowed,** although a total of ten respondents **(18%) were still married.** Important for care receipt purposes, over two thirds **(39; 68%) lived on their own.** Of the 18 participants who lived with others, eight (8) lived with their spouse only, and ten (10) resided with others. Of these ten (10) participants who lived with someone other than their spouse, six (6) had always lived with this person (most usually a child who had never left home):

> Well, she's never married. Actually, it's her that's buying the house here. She's always been at home.
> Respondent 136

For the most part, these six elderly people explained their cohabitation in terms of their care needs:

> I'd been ill and they decided I should come and live with them. I was living on my own. I was afraid of falling all the time. Anyway, I left Derby to come and live with Pat. I wanted to come up here mind, but they suggested it. I do miss some of my friends though. But I can't do very much now, and it does make me feel such a burden on her. But they asked me to come; they offered.
> Respondent 100. 86 year old woman now living with her daughter and son-in-law.[3]

The exception that stood out amongst these six elderly participants involved an 81 year old women who was caring for her physically handicapped adult daughter:

> Susan's always lived at home, hen. You see, she lost the power in her legs: infantile paralysis they used to call it, now it goes under polio. She was born in 1935 and her first operation was when she was one year old. She practically didn't come out of hospital until she was almost six. She never went to school or anything; they never had schools in the hospitals then. She can only walk with her zimmer. She wears a calliper, she used to wear two. She wore them both right up until the age of 28... No, (*she's never lived anywhere else*); where else would she have gone, hen? Her home is with me.
> Respondent 144

My interview with this particular elderly participant provided stark contrast to the notion that elderly people are always the passive recipients of familial and public support: this woman not only continued to take care of her daughter but had recently stopped home care assistants from providing her with domiciliary support because she felt able to continue to manage her household chores on her own.

The housing careers of the respondents exhibited a high degree of stability: **just under half (27; 48%) had lived at their present address for twenty years or more,** whilst a further ten respondents (18%) had lived at their present address for eleven to nineteen years. Only eight respondents (14%) had lived at their present address for less than five years. These results of course reflect the well known fact

[3] All names and places provided in quotations have been changed. Other changes regarding health status, gender and kinship have also been made when the level of detail provided in the quotation compromises anonymity.

that housing mobility is highly related to social class and age (Qureshi and Walker, 1989 p45). Furthermore, all but three of the respondents either rented or owned their home in their own right. In terms of tenure, **33 respondents rented their homes (58%), and twenty one (37%) owned their homes outright.**

A Description of Health

Elderly participants were asked to describe any long-standing illnesses or disability they experienced[4]; the more frequently cited of these is noted below. Other conditions included amputation, paraplegia, cancer and Parkinson's Disease.

Table 3.1: Elderly Participants' Health Complaints

N=57

AILMENT	n	%
Arthritis/rheumatism	27	47
Glaucoma	26	46
High Blood Pressure	17	30
Confusion*	17	30
Heart problems	17	30
Incontinence	9	16

* Respondents reported problems with confusion, usually in terms of not being able to remember things or recall recent events.

To highlight the broad patterns of health problems endured by the elderly people detailed in this study is an abstract exercise unless the illustration can be translated into their real experiences. Thus although Table 3.1 informs us that arthritis and rheumatism are the most common long-standing health problems, the actual responses provided by the elderly people emphasise a very different point: the multiplicity of their health problems and the difficulties that arise from multiple long-standing illnesses and disabilities:

[4] The wording of the question asked here was taken from the General Household Survey.

> I'm asthmatic but it's my back that's the problem. If I stand for any time, like cook anything, my back gives out. I had a colostomy and then I had the reverse done a year ago. And this *(left)* eye has gone. I had an operation in Edinburgh and I can see better with it like, but it's no right. They left it too long before doing anything. I was put on brufen for my arthritis and that perforated my intestines, so I had to have another operation after the colostomy. Then my husband took a stroke and I tried to pick him up and I had a hernia on both sides: I'm still wearing the surgical belt.
> Respondent 123

> I've everything but leprosy! I had a heart operation about 3 years ago; I had an aneurysm. And I had a cataract removed and I have glaucoma. I've had two heart attacks: so the doctor, he keeps an eye on me.
> Respondent 141

National statistics reveal that 44 per cent of all men and 56 per cent of all women aged 75 and over suffer from a limiting long-standing illness of some kind (OPCS, 1982 p140). My specific interest here however was not so much the specificities of medical conditions suffered by the elderly participants as in how long-standing illnesses and disabilities affected their ability to function independently in their own homes; after all, disability is not synonymous with dependency (Wilkin, 1990 p20).

I therefore recorded a number of pre-classified observed physical difficulties during the interviews as noted in table 3.2. These observations served to emphasise the ambulatory problems experienced by the great majority of respondents, and, as the words of the elderly participants spell out clearly below, such problems render the simplest of household and personal care tasks arduous:

> "It's *(Parkinson Disease)* limited what I can do. It takes me about two and a half hours to get up, washed and ready. I can't make the bed most times, and when I get the cramps and tremors, it's hellish. It's very painful...About a year ago I kept falling and I was black and blue...so my brother put the rails on the wall like that one there in the kitchen. I could do with some more (rails) to help me get around here."
> Respondent 105

Table 3.2: Health Related Problems Observed During the Interview

Observed Health Related Problem	n	% (N=57)
Walking Difficulties	46	81
Visual Impairment	29	51
Hearing Impairment	27	47
Crippled Hands or Legs	26	46
Uses Wheelchair	10	17
Shortness of Breath	8	14
Speech Problems	5	9
Coughs Continually	3	5
Skin Problems	2	3

"When my husband had his stroke we had to sell the car, so we've both been housebound for over three years. He's had several strokes and is in a wheelchair. There's lots of things the home helps are not allowed to do, so I have to get someone in to do it. That's all I can do. We have a man in to do the garden for us, and there's the window cleaner and the home help does the ironing. And I have very good neighbours if I run out of anything."
Respondent 123

"I can't get into the bath: I can't get my leg up, so I just wash down in here (sitting room), and when it's warm in the summer in the kitchen. Cooking is a nightmare; I'm really frightened at the cooker; so now I cook as little as possible. I don't really do much around the house. I have a wee feather duster and last week when the home help wasn't here I did around the fire...but then I collapsed in the chair."
Respondent 127

The multiplicity of health problems suffered by the elderly participants drew attention to the obvious, but nevertheless significant, finding that they were prone to acute, short term illnesses as well as chronic degenerative illnesses and disabilities. This had clear implications for their care needs. The caregiving literature tends to accord most attention to the chronic conditions that impede an elderly person's ability to function independently because it is these conditions which necessitate the sustained, long term, nature of caregiving designed to maintain elderly people in their own homes. From the responses given here

however, the care needs of elderly people also incorporate episodes of intensive, medically specialised, assistance. Consequently, the care needs of the elderly participants were volatile; they changed over time. Importantly, these needs were capable of moving both up and down in intensity from a need for "maintenance" type care designed to meet functional impairment resulting from chronic ailments, to highly "intensive" type care designed to alleviate the effects of acute conditions.

Flexibility in the level and type of care provision was therefore likely to be a notable requirement in meeting elderly participants' need for care. Unless the care provided allows elderly people to progress through a broad spectrum of different types and levels of supports, matching periods of increased need and dependency with intensified levels of care, the ability of the elderly person to remain at home is placed in jeopardy. Continuity and diversity are the keywords here: elderly people require a diversified system of care "services" that offers them continuity of care despite a changing care need base.

Functional Impairment

The fundamental criterion for the receipt of domiciliary services is that users display a certain level of (assessed) functional impairment brought about by physical or mental disabilities. To be "independent" demands, at the very least, that a person is able to eat, toilet, dress, wash, and move around their home as necessary: tasks known as "activities of daily living" (ADL). But many other functions are also associated with independence, and the more complex the society in which a person lives, the more functions a person must be able to undertake. Included in a secondary list are activities such as the ability: to manage money; to use equipment such as telephones; to cook, clean and undertake the laundry; to be able to get from one place to another via the necessary means of transport; and to read and write. These activities are known as "instrumental activities of daily living" (IADL). Clearly, not everyone needs to be able to do every single instrumental activity. Indeed, gender stereotypes and the ability to purchase activities from someone else in the form of services affect the likelihood of an

individual actually undertaking an activity personally. But if an elderly person's physical or cognitive impairment precludes them from undertaking those tasks necessary to function in their home environments, then in all likelihood, they are candidates for domiciliary care services.

While the development and application of dependency scales is nothing new in gerontological research (e.g., Askham et al., 1992; Bury and Holme, 1991; Katz et al., 1963; Lawton et al.; Pfeifer, 1975; Qureshi and Walker 1989), it was difficult to address the elderly participants' receipt of domiciliary services and their reactions to those services without first examining the levels of functional impairment they were exhibiting at the time. With this in mind then, respondents were asked to identify the degree of difficulty they encountered in undertaking 13 key tasks necessary for independent living. These 13 items are common to a variety of scales which measure functional impairment, include activities of daily living items and instrumental activities of daily living items, and are as follows: taking a bath or shower; getting in and out of bed; getting from one room to another indoors (including using stairs if there are any); using the toilet; walking to the bottom of the road; preparing a main meal and clearing up afterwards; grocery shopping; managing finances, (the actual question focused on the collection of participants' old age pension and payment of electricity bills); using the telephone; light housework (defined as dusting); heavy housework (defined as spring cleaning/changing the curtains); light laundry (washing a blouse or shirt and underwear); and heavy laundry (washing a blanket or duvet).[5]

Decisions regarding which ADL and IADL items to include in the study were determined by a concern to keep the instrument simple yet comprehensive enough to discriminate between different levels of need in the four key areas of mobility, personal care, instrumental care and finances. Specifically, respondents were asked to indicate whether they are able to complete each task on their own with no

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[5] During the pilot study, I also asked respondents about gardening, decorating, cutting toenails, washing hair, making and attending appointments. Although Qureshi and Walker's study (1989) identified a particular need for chiropody services, I decided to abandon these categories when measuring functional impairment because of time limitations.

difficulty; on their own but with difficulty; or whether they are completely unable to do it on their own and therefore require the assistance of somebody else[6]. Previous research has used this approach as a way to establish an "objective" indication of the need for care by elderly people (Qureshi and Walker, 1989 p71). I retain a certain scepticism about such objectivity for three main reasons: the notion of difficulty is ambiguous and open to interpretation; elderly people adapt their lifestyles in order to mitigate the difficulty they experience; and elderly people will not admit to difficulty in their quest to maintain their independence (Braithwaite, 1990 p1; Qureshi and Walker, 1989 pp18-19). Furthermore, whether an elderly person is "unable" to do a certain task unaided, whether an elderly person finds a certain activity "difficult" and indeed whether an individual encounters "no difficulty" whatsoever, is, in part, a function of their environment and their ability to purchase consumer durables and other products (Dant, 1990 p21).

The elderly participants give voice to these reservations very well in their quotations below. Their words illustrate the inadequacy of "objective" dependency scales as precise indicators of care needs because they fail to take account of personal preferences, resources and informal supports:

> (*regarding having a bath*) They've been trying to sort this one out. They sent this woman and she said: "Come on, get your stuff off, I'm going to give you a bath." Anyway, I took off everything apart from my underpants; I wasn't taking them off! But I stopped her coming again. No hen, I take a shower on my own like. It's hard like and I have to take my time, but harder still having a stranger wash you.
> Respondent 120 (male)

> *(regarding preparing a meal)* Oh I manage. I just do something I can put in the microwave; a tin of soup or one of those ready meals. You know you can get a lot of packet stuff you can put in the microwave...No, I manage all right with my cooking...I don't eat a lot nowadays; I don't eat like I used to."
> Respondent 126

[6] The scoring method used was taken from the Qureshi and Walker 1989 study. Respondents scored: 2 if completely unable to do an activity; 1 if they could do the activity but with difficulty; and 0 if they were able to do the activity without difficulty.

(*regarding light and heavy housework*) I had a home help, but he left. He got transferred to another area, so I'm waiting for another one to come. But no-one has come for a fortnight or more. But as long as I can carry on mesel', I'll no bother them, (*the Social Work Department)*...I've got some good neighbours; the old lady across the way will give me a hand and that. But really, I think I can manage mesel'.
Respondent 103

The Level of ADL and IADL Functional Impairment Described by Participants

Table 3.3 below provides an overview of elderly participants' functional abilities and reveals that elderly participants experienced most difficulty with those tasks associated with lifting, carrying, and walking. It is important not to lose sight of the fact that all of the elderly participants were domiciliary service users and thus were highly likely to exhibit moderate levels of functional impairment as defined by ADL and IADL measurements. What is more interesting about table 3.3 perhaps is that it contains several apparent inconsistencies in the results. For instance, whereas a total of 47 participants (83%) stated that they were either unable, or found it difficult to walk to the bottom of the road, a lesser 38 (67%) found it either impossible or difficult to collect their pension or pay an electricity bill. Similarly, whereas 26 elderly participants (46%) stated they were completely unable to take a bath or shower on their own, only three (5%) also stated that they were unable to go to the toilet on their own.

In both these instances, the skills demanded of the participants are very similar: collecting a pension and walking to the bottom of the road both demand a certain level of physical mobility; getting into and out from a bath or shower and getting on to and off from the toilet both demand a certain degree of physical agility. One explanation for the apparent inconsistencies in elderly participants' descriptions of the difficulty they encountered may be that they attributed different importance to different ADL and IADL items and were prepared to struggle harder in order to undertake certain task before admitting to difficulty. In particular here, finances, ablutions and toileting are all tasks which are conducted in private. It may be

therefore that social mores impinge upon the results obtained from ADL and IADL scales.

A problem with the functional assessment scale deployed in this study, and indeed with ADL/IADL scales in general, is that it attributed equal value to each of the tasks measured. An interesting research project would be to see what importance elderly people themselves attached to each task, to attach their weighting factors and then compare the levels of "dependency" produced with those denoted by equal weighting factors.

Table 3.3: The Measurement of Elderly Participants' Functional Ability

N=57

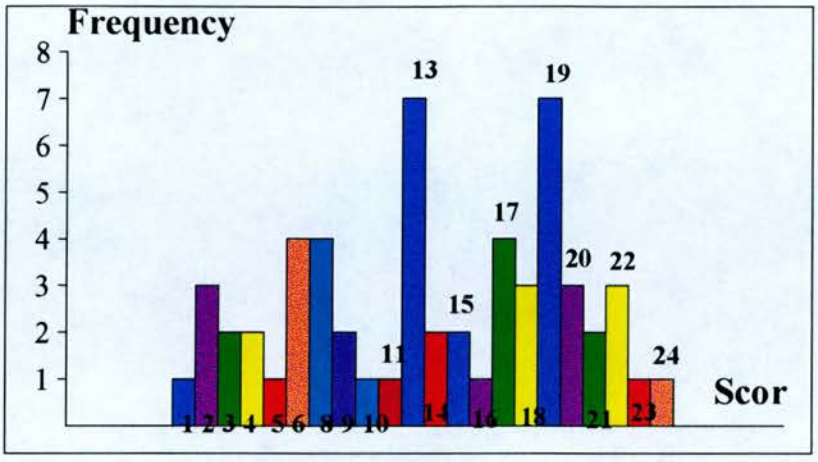
TASK	UNABLE n (%)	DIFFICULT n (%)	ABLE n (%)	DIFFICULTY RANK
Heavy Housework	48 (84)	8 (14)		1
Grocery Shopping	37 (65)	13 (23)	7 (12)	2
Heavy Laundry	36 (63)	9 (16)	12 (22)	4
Walk to Bottom of Road	34 (60)	13 (23)	10 (18)	3
Light Laundry	26 (46)	11 (19)	20 (35)	9
Bath/Shower	26 (46)	18 (32)	13 (23)	5
Light Housework	21 (37)	21 (37)	15 (26)	6
Prepare main meal and clear up	19 (33)	21 (37)	17 (30)	7
Pension/Electricity Bill	16 (28)	22 (39)	19 (33)	8
Use Telephone	5 (9)	8 (14)	44 (77)	13
Use Toilet	3 (5)	18 (32)	36 (63)	12
Getting in/out of Bed	2 (4)	22 (39)	33 (58)	11
Getting around indoors		31 (54)	25 (44)	10

The ADL and IADL items are ranked in table 3.3 above in terms of the absolute numbers of elderly people who stated they were "unable" to conduct the relevant activity. In terms of providing a proxy for the need for assistance from others however, it is perhaps more useful to combine the "unable" and "difficult" columns; this is denoted in the column entitled "difficulty rank". For the top two activities that elderly participants found most difficult (heavy housework and grocery shopping), amalgamation of the "unable" and "difficult" columns made no difference. But whereas doing light laundry ranks fifth in terms of the number of elderly participants who said they were "unable" to conduct this task for themselves, it achieves a lesser rank of ninth when the "unable" and "difficult" categories are amalgamated. A criticism I would apply in retrospect to my questions here is that I did not check whether or not elderly participants had a front loading washing machine; I suspect that the difference identified was accounted for by whether participants had such machines as opposed to twin tubs or no washing machine whatsoever.

In terms of translating a scale of functional impairment into an indicator of need for daily help, a numerical value was attached to each task depending upon the degree of difficulty encountered by the individual. In this study, "unable" carried a score of two (2); "difficult" a score of one (1), and "able" a score of zero (0). Again, it is important to remember that no differentiation is made between the 13 activities in terms of importance accorded to them by the elderly participants. In theory therefore, an individual's particular score could range from 0, (indicating no requirement for any assistance whatsoever), to 26 (indicating complete reliance on assistance from others). **The actual scores ranged from 1 to 24, with a mean score of 13 and modal score of 19.** As the histogram below illustrates, however, the actual distribution of scores displayed a bimodal tendency suggesting that further analysis was required here: the impact of gender and age upon respondents' ADL scores were also obtained.

Chart 3.1: The Distribution of ADL/IADL Scores

N=57



Total ADL scores were divided into quartiles and the chi-square statistic was first calculated according to gender and then by the age of the elderly participants. Tables 3.4 and 3.5 below catalogue the results.

Table 3.4: Total ADL/IADL Scores Organised by Gender

Total ADL Score	Male n	Female n	Total n (%)
Low: 1 to 6	6	7	13 (23)
Moderate: 7 to 12	1	7	8 (14)
High: 13 to 18	5	14	19 (33)
Very High: 19 to 24	6	11	17 (30)
Total	18 (32)	39 (68)	57

First, table 3.4 illustrates that there was a "dip" in the number of participants with "moderate scores": total scores were concentrated in the "low" score category or "high" and "very high" categories. Overall however, 37 per cent of the sample had "moderate" or "lows" scores while 63 per cent had either high or very high scores. This is not particularly surprising when one recalls that all of the elderly participants were domiciliary service users who had already been assessed and met

service eligibility criteria. Table 3.4 immediately reveals one notable difference between the male and female participants however: 18% of the 39 elderly women interviewed had a total ADL score of 6 or below (indicating a high degree of functional ability), compared with exactly one third of the men. Of course, the numbers involved in this study are too few to allow for extensive statistical testing. Caveat aside however, this finding is reminiscent of larger scale research which points towards a gender bias which favours men over and beyond assessed functional impairment in the distribution of domiciliary services (e.g., Evandrou et al., 1986). In other words, it would seem that the principle whereby elderly men do not need to be as functionally impaired as elderly women in order to receive formal support in the form of domiciliary services also holds true for my sample of elderly service users.

Of course, it is also known that one's age has a very strong influence on functional ability and that the "old old" endure the highest levels of functional impairment. Accordingly, table 3.5 reveals that 55% of elderly people with either high or very high ADL scores are aged 80 or over. Furthermore, of the 14 participants aged 85 and over, 71% scored either high or very high ADL scores.

Table 3.5: Total ADL Scores by Age

Total ADL Score	65-69	70-74	75-79	80-84	85 and over	Total (%)
Low: 1 to 6	-	2	4	5	2	13 (23)
Moderate: 7 to 12	-	2	1	3	2	8 (14)
High: 13 to 18	2	2	3	5	7	19 (33)
Very High: 19 to 24	1	2	6	5	3	17 (30)
Total (%)	3 (5)	8 (14)	14 (25)	18 (31)	14 (25)	57 7

Advancing age is therefore associated with a decline in functional independence, but whether this automatically results in a loss of personal autonomy depends upon the nature of the care received (Arber and Ginn, 1992, p89). Nevertheless, the ADL scale is a useful tool for identifying the respondents' functional impairments in the key areas of personal care, instrumental care, mobility and financial management. But, in terms of measuring a person's actual need for care, its application is perhaps more limited. As the following quotation reveals however, what the ADL scale illustrates is a person's vulnerability, not their actual need:

> I have a seat on top of the bath that's been fitted for me. They fitted it a couple of years ago. It's very good. I don't use the upstairs really; just keep my clothes up there. We brought the bed down for the wife *(who died almost two years ago),* but I use it down here now. I don't have meals on wheels; the wife and me tried them, but we detested them. I don't like to cook at all, so I buy those ready meals you just have to heat up. But I'm trying to cut down at the moment. I have a washing machine I use, but anything I leave lying out, my daughter-in-law grabs it and takes it away with her on a Sunday when she comes for the sheets. The home help does the main messages (*shopping*), on a Thursday, but I go up most days to (*supermarket),* just to see what they have; see if there's anything different. Respondent 146

Summary and Conclusions

This chapter has provided an introduction to the theoretical and empirical critiques upon which a significant part of the remainder of this thesis is grounded. It has argued that a substantive and significant gap in the care literature concerns the exiguous attention accorded to the needs, experiences and preferences of care receivers and has issued a challenge to research which is limited to an examination of family carers; not care receivers and most certainly not the caring relationship. Fundamentally, three levels of analysis are pertinent to the long term care of frail elderly people: the individual, the family and society. Within each of these levels, the outstanding task is to place elderly people themselves at the centre of the analysis. For instance, at the level of the individual, one of the most important questions addressed by social theorists concerns the nature and effects of social bonds that relate one individual to another (Nisbet, 1970). Within the care

literature this enormous issue has often been reduced to an examination of "why women care": ways in which elderly people request, or otherwise make known, their needs and preferences for family care, and the changes that this engenders in their relationships with their relatives remains largely unknown. At the family level of analysis there is an hiatus in knowledge about the dynamics which underpin the organisation of family care to frail elderly: dynamics which include the affectual and functional relationships between elderly people and their families and which form the basis of family care. Such dynamics could help answer why filial care is largely unshared care between siblings, contribute towards a better understanding of the contours of intergenerational exchange and reciprocity and further debate about theories of distributive and familial justice. At the societal level, oversight of the care recipient perspective means that identification of the ways in which frail elderly people's dependency is "structured" by the allocation criteria and delivery practices of domiciliary services is obscured from public view and consequent debate.

This chapter also introduced the sample of elderly participants to the reader in terms of demographic and health profiles: the participants were predominantly female, "old old", widowed and living alone while their descriptions of their health revealed that it was the multiplicity of conditions which resulted in functional incapacity. Finally, the chapter provided a brief critique of functional dependency scales and presented an overview of the participants' functional impairments as measured by one such catalogue of ADL and IADL tasks. Although results revealed a strong positive association between functional inability and age the association between functional inability and gender was not significant as I had previously expected. Very important here, the more qualitative data I obtained at this point during the interviews with elderly participants revealed that it was the ways in which elderly participants responded and adapted to their functional inabilities which was important in terms of devising indicators of need for help from others.

The next chapter addresses elderly participants' receipt of family help.

4

IDENTIFYING PRIMARY CARERS: ELDERLY PARTICIPANTS' CARE NEEDS AND THEIR RECEIPT OF ASSISTANCE

Introduction

The apportionment of kinship responsibilities has been of moral and practical concern since the days of antiquity when Cain first raged about the matter (Genesis 4: 9). Divine entreaty aside however, the issue of family care has attracted widespread attention from researchers, politicians, administrators and journalists alike. Responsibility for this accentuated political, academic and popular prominence rests with a number of now familiar demographic, economic and sociological developments.

Demographically, the ageing of the population, in particular the disproportionate growth of very elderly cohorts, increases the likely demand for care because of a positive correlation between age, chronic ailments and functional impairment[1]. This has encouraged debate about the public "affordability" of long term care services and has focused attention on the desired balance of responsibility between the state and the family in terms of the care provided to elderly people.

Economically, women's increased levels of participation in the labour market (Martin and Roberts, 1984), have raised concerns about their future capacity as traditional family carers to provide care at levels necessary for the increasing numbers of very old elderly kin. This in turn has highlighted the availability of public services as family members begin to behave as quasi care "managers" in

[1] see Hunt, 1978; Phillipson and Walker, 1986; Henwood, 1990; and Glendinning, 1992 for an overview of demographic forecasts and projected increases in supports required by elderly people.

terms of accessing a supply of public long term care services for their elderly relatives (Waerness, 1990 p123).

Sociologically, it is the transformation of the family, (primarily in the form of shrinking size, increased rates of divorce, and greater geographical mobility), which has raised questions about the responsibility for elderly kin.

Dramatic forecasting regarding the consequences of each of these developments underpins the heightened interest in the politics that determine and deliver services provided under the rubric of community care (e.g., Audit Commission, 1986; Department of Health and Social Security, 1981; Henwood, 1986; Walker, 1982). In particular, prevailing community care philosophy increases the need to identify and understand the factors that are related to the provision of informal, or family, care to frail elderly people:

> Whatever level of public expenditure proves practicable, and however it is distributed, the primary sources of support and care are informal and voluntary...It is the role of public authorities to sustain and, where necessary, develop - but never to displace - such support and care. Care *in* the community must increasingly mean care *by* the community. Department of Health and Social Security, 1981, p3.

Mapping informal carers, understanding their motives to care and evaluating the effects of providing such care are commonplace topics within caregiving research (e.g., Green, 1988; Arber and Green, 1990; Henwood and Wicks, 1984; Evandrou et al., 1986; Ungerson, 1987; Qureshi and Walker, 1989). Criticisms which may be levelled at this established research agenda concern the preoccupation with the activities and motivations of "primary caregivers" and the bypassing of experiences of care receivers (Arber and Ginn, 1991), and other family members implicated in familial care arrangements (Abel, 1987; Brody, 1985). In terms of caregiving, as opposed to care receipt however, an important first development in caregiving research has been the disaggregation of family caregiving according to different family relationships (Brody et al, 1988; Horowitz, 1985; Matthews et. al., 1989; Qureshi and Walker, 1989).

This chapter identifies the main sources of care received by the elderly people who participated in this study. The chapter is primarily based upon the descriptive accounts provided by elderly participants. The chapter begins with an overview of the all sources of assistance received by the elderly participants for the 13 different ADL and IADL tasks introduced in the previous chapter. It then concentrates on the provision of family care only and disaggregates the main source of that care according to gender (of both care recipients and carers) and levels of functional impairment pertaining to the care recipients.

The Study Data

This research identifies the family dynamics of family care for elderly people from a dual perspective: the elderly care receivers and the adult children nominated by their parents as their "main family helpers". This chapter concentrates upon elderly people's descriptions of the care they received and thereby identifies family carers from the perspective of those elderly care receivers. As such, the chapter deliberately places the elderly care receivers' descriptions and experiences of family care at the centre of analysis.

The Source of Care: Provision and Provisos About Receipt

The sampling strategy means that we may be sure that each elderly respondent received some form of domiciliary support from the Social Work Department. The sample of elderly people interviewed should thus not be taken as representative of all functionally impaired elderly people living in the fieldwork area. This is an important proviso to bear in mind when examining the results presented below. A second point of preamble is that this chapter addresses the "main" sources of help identified by elderly participants. With regard to family care, the usual term deployed in the literature is that of "primary carer". This term was deliberately avoided during interviews with elderly participants; rather elderly participants were asked to describe their "main" helpers for individual tasks.

The amount of family help received by elderly participants and the identity of their family carers was established via their identification of up to two people who helped them with each of the 13 ADL and IADL tasks and whether this help was enough for each task. The intention here was not to prompt elderly people about the family help they received and the approach followed allowed elderly respondents to indicate the variety and extent of help they received from all sources (family and formal) and its overall adequacy. The form of questioning also allowed elderly participants to identify any care gaps for each of the ADL and IADL tasks. The issue of secondary carers is an important one for the purposes of this thesis and deserves substantive discussion: this is done in chapter six. This chapter is limited to a discussion of the "main" carers identified by elderly participants.

After dealing with each of the ADL and IADL items in turn, elderly participants were asked to think only about their family and to nominate the family member they "relied upon the most" as well as the family member they "next most relied upon". This means, of course, that the "primary **family** carer" as nominated by the elderly care receiver may not necessarily have been their "**primary** carer": this could be have been a paid home help or a non family carer. In order to pinpoint exactly whether any elderly participants ascribed a greater importance to help received from non-familial sources, they were also asked to identify anyone who provided them with more help than any individual relative.

Tables 4.1 to 4.4 below catalogue elderly participants' nominations for their "main helper" for each of the 13 ADL and IADL tasks. A notable feature common to the majority of these tables concerns the continuing abilities of elderly participants: **at least 60 per cent of elderly participants indicated that they received no assistance whatsoever for six of the 13 tasks addressed** (taking a bath or shower, using the toilet, getting undressed and into/out of bed, walking to the bottom of the road, getting from one room to another and using the telephone). This result is reminiscent of other research which stresses the paradoxical independence of "disabled", "dependent" elderly people (e.g., Hunter et al., 1988).

The tables also reveal a number of care gaps and illustrate that elderly people fail to ascribe any consistent predominance to family care in comparison with formal care.

More specifically, table 4.1 catalogues the assistance received for three "personal care tasks" (having a bath or shower, using the toilet and getting undressed and into bed). It highlights that **42 per cent of elderly respondents indicated a need for more help with bathing;** neither family nor formal services fill what is obviously a significant "care gap". Personal hygiene is of course bound up with physical health and psychological well-being and there is something both pathetic and enraging about an elderly person being unable to keep as clean as they would wish:

> I'm 89; I cannae do very much now....It's sometimes 6 or 7 weeks before you see the nurse. But they cannae come that often, they're so busy. My friend, (also elderly, approximately 71 years of age), comes over to see me, so she'll give me a bath if I ask her. But you cannae depend on the nurses, they haven't the time. But it's no right, 6 weeks before a bath, it's no right."
> Respondent 115

> I have a bath seat and the lady comes on a Friday to give me a bath. Anyway she came last Friday and afterwards she told me she wouldn't be back until...*(almost three months away)*. So I suppose I'll just have to struggle, to top and tail until then.. Before all this, I used to love my bath: to be able to lie in the bath and enjoy it - you know. But now I'm in and out; she doesn't hang about you know "
> Respondent 125

Within the tables, the category described as "no help received" means either that the elderly person does this task for him/herself, or that the task does not get done. Table 4.1 below reveals very high levels of no help received for each of the three personal care tasks. This is disturbing when compared with relevant levels of expressed difficulty. For instance, in terms of having a bath, 60 per cent of respondents received no help and were thus either self sufficient or unable to bathe or shower: this is despite the fact that over three quarters (77%) of elderly participants previously indicated that they either had difficulty, or were completely unable, to bath themselves.

Table 4.1: Source of Main Help Received For Personal Care Tasks

N=57 (%)

TASK	BATH/SHOWER	USE TOILET	UNDRESSING AND INTO BED
No Help Received	34 (60)	52 (91)	50 (88)
Need MORE Help	24 (42)	3 (5)	5 (9)
Family and Other	12 (21)	3 (6)	6 (11)
Paid Worker	11 (19)	2	1

In light of this difficulty, **it is perhaps surprising that only 42 per cent of respondents expressed a need for more help in having a bath**. The observation was made in the previous chapter that functional limitation scales do not necessarily translate into actual need. This result reiterates this contrast between objectively measured and subjectively defined care needs. Keeping to the example of bathing, the provision of aids such as a bath seat and wall handles may well reduce, even obviate, the need an elderly person has for assistance. Nevertheless, the discrepancy between levels of expressed difficulty and desired help is a good example of how elderly people struggle to maintain their "independence" despite difficulty in doing so:

> I can get into the bath but it's a struggle like. I have a wee stool and some handles: I just have to take my time.
> Respondent 121

> It's getting out of it that's the problem, so now I try to have it the morning when the home help's here. I just have to take my time; with this tinnitus I lose my balance a lot. But if I have it when she's (home help) here, I can call out.
> Respondent 126

The preferences of care receivers are highly salient to the calculation of care "needs". "Objective" need for care indicators (a good example is used by Qureshi and Walker, 1989, p74), are based upon the degree of difficulty expressed by an elderly person in undertaking a task and the amount of assistance they subsequently receive. Results here suggest that caution is required when extrapolating care needs from such objective measurement matrices. Subjectively stated care needs may differ from their objective counterpart; they may be

contingent upon personal preference rather than functional ability. Furthermore, discrepancies between objectively measured and subjectively defined needs may complicate both family carers' and formal assessors' estimations concerning the type and level of assistance required. A worst case scenario is when an elderly person's refusal to accept necessary assistance compromises their health or safety. Such a scenario may also pose an ethical dilemma: whether to intervene or not. In terms of family care, each family carer has to make decisions about the scope, level and point at which care provision begins. There are no absolute rules available for carers to apply, but the views and opinions of their elderly kin are highly relevant to the quality of support family carers can provide if only because such views will affect the level and scope of care that will be accepted by and acceptable to care receivers.

Finally here, table 4.1 reveals that **very few elderly respondents were helped in using the toilet (9%), or indicated any desire for such help (5%)**. Indeed, even amongst the five people who were helped with using the toilet, there is evidence to suggest that it was received reluctantly:

> I have to have help using the toilet: I can't take my trousers down. I was really hoping they'd catheterise me so at least it wasn't that often, but they won't. The nurses toilet me and my daughter does it at night and before she goes to work. But from next week it'll be the home helps; I'll have to get used to them.
> respondent 136

For personal care tasks at least therefore, social mores may also interact with functional ability and alter care receivers' assessment of their needs. Personal care tasks are likely to be among the very last undertakings that elderly people are prepared to relinquish to a carer, and any provision of aids to ease the difficulty they face is likely to be preferred to actual assistance.

For the examination of care with household management, respondents were asked to identify their main sources of support for five tasks: light housework (described as dusting and tidying up); heavy housework (described as spring cleaning); light laundry (described as washing underwear, socks and tights); heavy laundry

(described as bedding); and cooking (described as preparing a main meal and clearing up afterwards).

Table 4.2: Source of Main Help Received for Household Management

N=57 (%)

TASK	LIGHT H/WORK	HEAVY H/WORK	LIGHT LAUNDRY	HEAVY LAUNDRY	COOKING
No Help Received	7 (12)	11 (19)	27 (47)	24 (42)	23 (40)
Need MORE Help	20 (35)	31 (54)	13 (23)	30 (53)	17 (30)
Family and Other	11 (20)	28 (49)	17 (30)	18 (32)	20 (35)
Paid Worker	39 (68)	18 (32)	13 (23)	15 (26)	14 (25)

Of course housework, laundry and meal preparation are key areas of responsibility for home helps and it is important to note that 95 per cent of respondents received this domiciliary service (reported in more detail in chapter seven). Fundamentally however, the results presented in table 4.2 above reveal a dichotomy in terms of help elderly participants received for household tasks: relatively few elderly respondents were without any help for housework in comparison with 40 per cent or more for laundry and cooking. **The overwhelming source of support for light housework came from domiciliary workers not family carers**: over two thirds (68%) of respondents indicated that their home help[2] was their major form of support. For the other three tasks however, family carers predominated over domiciliary workers. Finally, table 4.2 provides more evidence of gaps in the care elderly people identify as necessary: for instance, **54 per cent of elderly participants stated that they needed more help with heavy housework, while 35 per cent expressed a need for more help with light housework.**

The third type of ADL and IADL tasks examined were financial management skills as indicated via collecting a pension or paying a bill and shopping for groceries. Because these two tasks require a certain degree of physical mobility

[2] The term "home help" is used consistently throughout this thesis: not one participant used the term home care assistant.

(not to mention strength in terms of pushing trolleys and carrying bags), I also asked elderly participants about any help they received with walking to the bottom of the road in order to be able to isolate the effect of physical impairment upon cognitive skills regarding handling money and budgeting. Table 4.3 summarises the results here and reveals that while 68 per cent of elderly people were not assisted in any way in their efforts to walk to the bottom of the road in which they lived, over half (53%) stated that they need more help for this activity. It is important to recall here that over 82 per cent of the elderly participants had previously stated either that they had difficulty with, or were completely unable to, walk to the bottom of their road on their own. **This suggests that a considerable proportion of respondents are effectively housebound because they can not obtain the help they need in getting out of their homes**. Levels of care receipt were considerably higher for the pension and grocery shopping items whilst the identified care gaps were much slimmer.

Table 4.3: Main Source of Help Received for Financial Household Tasks

N=57 (%)

TASK	WALK DOWN ROAD	PENSION/ BILLS	GROCERY SHOPPING
No Help Received	39 (68)	18 (32)	10 (17)
Need MORE Help	30 (53)	1	7 (12)
Family and Others	16 (27)	22 (38)	29 (51)
Paid Worker	2	17 (30)	18 (32)

Finally, respondents were asked about their ability to move from one room to another in their homes and whether or not they could use the telephone unassisted. The purpose of including these tasks was to identify any elderly people who were effectively "room bound" and also to check that respondents could contact the outside world should they need to do so. As table 4.4 reveals below, very few elderly participants received any help whatsoever for these two tasks.

Table 4.4: Main Source of Help Received for Indoor Mobility

N=54 (%)

TASK	Indoor Mobility	Use Telephone
No Help Received	55 (97)	52 (91)
Need MORE Help	8 (14)	1
Family and Others	2	5
Paid Worker	-	-

At first sight, participants' reports of very low levels of help received and minimal indications of extra help required suggested that they experienced little or no difficulty in getting around indoors. Such independence however is belied by a previously reported finding; 54 per cent of the elderly participants previously stated that they experienced difficulty getting around indoors.

There is, of course, a sense of foreboding which prevents elderly people from giving up their home. Perhaps it is not surprising therefore that respondents' actual remarks here revealed they had adapted to the limitations imposed by the layout of their home rather than vice versa. For example, several respondents used downstairs rooms only and had effectively shut off the first floor. For one elderly man this meant having to use a chamber pot in the one room in the house in which he lived; a state of affairs about which he was very unhappy. The increase in levels of owner occupation, the emotional trauma of moving home, not to mention the physical effort and financial cost required to do so, all underpin the low level of housing mobility pertaining to elderly people. Such inhibitors aside however, inappropriate housing compounds and complicates the effects of physical frailty:

> I don't get out the now; I cannae get down the stairs out the front door. The only times (sic) I get out is when my friend takes me out in the car. I haven't any confidence in walking. I can't get in the bath, so I just wash myself with the one hand that I can use *(right hand paralysed through a stroke)*. I can't get up the stairs so I have to use a commode (*in room in which the respondent lives)*. My home help empties it for me. I manage with the commode but I don't like it: can you smell it in here? ... That's why I'm looking forward to the chairlift to get me up the stairs; I'm waiting on one with Scottish Homes. I'm an independent fellow you know, but since I've come out of hospital there's lots of things I cannae do. I was in the hospital for five months (*after a stroke*). I manage some things though; I manage to put my washing in the washing machine but the home help has to get it out."
> Respondent 148

> I can't have a bath because I can't get out, and getting around indoors is getting difficult. If I go to the top of the stair I'm short of breath at the top. But we won't move hen; our son helped us buy this. We do our own messages but we have to take a taxi. And I can't go alone; Jeff (*husband*) has to come. That taxi ride thing (*concession scheme*) is good; you get it through the council. I just do the ironing periodically; if I iron a bit, that's it, my arm is gone. Old age doesn't come by itself, hen."
> Respondent 145

Disaggregating the Provision of Family Care

Disaggregating the provision of family care according to variables such as gender and kinship is a key component of the social policy approach to the analysis of family care. A principal concern here is to identify any qualitative and quantitative differences in care provided by different types of carers and to measure their impact. Different carers, of course, share certain characteristics in terms of their motives to care for elderly parents, the tasks undertaken in providing care and the effects of doing so. Although carers may share certain characteristics however, every carer has a different story to tell. Indeed, the findings of studies which disaggregate the provision of family care serve to emphasise the important points that the ways in which someone becomes a carer, the types of care they provide and the effects of doing so, are the product of a unique interaction between biography, socialisation, geographical proximity and socio-economic circumstance.

a. Gender: The Research Evidence

Although empirical and conceptual analyses of the provision of care to elderly kin by men are fewer than those which deal with care provided by women, to argue that men are "forgotten" in caregiving research (Arber and Gilbert, 1989) is to exaggerate. The impact of gender has been, and continues to, a major preoccupation within caregiving research (e.g., Bytheway, 1990; Wilson, 1995) and is understood to affect the likelihood of becoming a carer, to make a substantial difference to the types of caregiving undertaken and to affect the consequences of the provision of such care.

Localised studies aside (e.g. Briggs and Oliver, 1984; Levin et. al., 1989), the 1985 Informal Carers Survey provided the first nationally representative data on family carers and revealed more male carers than previous estimated (Green, 1988). More recently, the 1990 General Household Survey (GHS) illustrates that 13% of men, in comparison to 17% of women, look after, or provide some regular service for, someone who is sick, elderly or handicapped (OPCS, 1992). Using the OPCS definition, there are an estimated 6.8 million carers in Great Britain; 2.9 million men and 3.9 million women (ibid). Elderly men are far more likely to be carers than their younger counterparts because the majority of male carers are spousal carers. Spousal presence is known to override the impact of gender in the determination of carer "selection" (Qureshi, 1990; Qureshi and Simons, 1987; Qureshi and Walker, 1989, p123; Baldwin and Twigg, 1991, p120).

But even though elderly men provide the same amount of co-resident care for their wives as elderly women do for their husbands (Arber and Ginn, 1990 p429), significant gender differences persist amongst younger carers both in terms of the provision of care and in the magnitude of that provision (Green, 1988; OPCS, 1992). Women are more heavily involved in the heavy end of caregiving than men (OPCS, 1992); they account for two out of every three of those caring for 20 hours a week or more (Green, 1988). Consequently, caring remains very much a women's issue (Baldwin and Twigg, 1991; Braithwaite, 1990; Morris, 1992).

With regard to any gender specificity in tasks undertaken, an important early study uncovered major sex differences in terms of employment, housework, personal care provision and dependency levels between single daughters and single sons caring for elderly parents (Wright, 1983). For instance, all but one son worked full-time and none had varied their working hours in order to accommodate their caregiving responsibilities. By way of contrast, less than half the daughters worked full-time; and over a third were not in any employment. Several daughters had changed from full to part-time employment, or worked flexible hours in order to care for their parents. Most of those in employment reported that they lost time at work on a regular basis. Sons received more assistance from home helps in caring for their parents than daughters, whilst the elderly mothers who lived with sons were more active domestically than those who lived with daughters. Furthermore elderly mothers who lived with daughters required more help with personal care than those who lived with sons. Finally, sons were more ready to refer their parents to residential care than daughters. Wright explained her findings in terms of sex-role expectations and how they not only influence the amount of dependency elderly parents "permitted" themselves but also the amount of dependency the sons and daughters "tolerated".

Qureshi and Walker also addressed gender differences in the provision of care and were "surprised" by their extent (Qureshi and Walker, 1989, p90). Excluding husbands from their analysis, they catalogued these gender differences in terms of ratios and found that: for light shopping the ratio of women to men was 6:1; for heavy laundry it was 22:1; and for light laundry it was 40:1 (ibid). Including husbands, women were 33 times more likely than men to help with heavy laundry when their elderly relative was unable to do so personally (ibid., p91). Gardening and decorating represented the only tasks where male carers predominated over female carers, but even here, when the elderly person was completely unable to perform these functions, women were as likely as men to provide the necessary assistance (ibid., p91). They concluded:

> ...female relatives predominated as principal carers and, although men made important contributions to some aspects of caring and tending, it was women who were most likely to be responsible for the whole range of personal care, household management and maintenance tasks and particularly so when their elderly relatives were severely disabled. It appears that with some exceptions, especially among husbands, men were able to choose which activities they helped with whereas female carers did not have such flexibility."
> Qureshi and Walker, 1989, p91.

In terms of time spent caregiving, a small scale study of families caring for severely disabled elderly relatives found significant differences between men and women. The average time devoted daily to caregiving on weekdays was 3 hours 24 minutes: of which 3 hours 11 minutes were spent by wives and 13 minutes by their co-resident husbands (Nissel and Bonnerjea, 1982, p21).

Of course, the usual explanation of why women predominate over men as family carers to elderly kin is couched in terms of the psychological and societal constructions of the female identity (see chapter 9), and because societal norms, emphatically underpinned by public policy, make it difficult for them to refuse to do so (Arber and Ginn, 1992; Finch, 1989; Finch and Mason, 1990; Ungerson, 1987). Such underpinning is evidenced by research which reveals that the level of support offered by social services to elderly people is differentiated according to the genders of both the elderly service users themselves and their carers; basically, elderly men whose family carers are also male are likely to receive the highest levels of formal support. In this way, the allocation of formal services effectively operates to sustain the sexual division of labour in which women are considered to be the normative providers of care (Twigg, 1990). The supposition therefore, if not the reality, is that men have more effective discretion than women in choosing whether or not to provide care for their elderly kin and over the form any care will take.

North American research tends to confirm the preponderance of female carers and the importance of female kinship networks in carer selection hierarchies. Interestingly however, a number of studies uncover certain similarities between male and female carers. With regard to gender differences for instance, Amy

Horowitz found that of 32 caregiving sons, 88 per cent were either the only child, one son out of a family of all sons, or the only geographically proximate child. By way of contrast, less than half of 99 caregiving daughters were in such kinship networks (Horowitz, 1985, p614). In terms of similarities however, she found that sons were no more likely than daughters to care for: fathers as opposed to mothers; older parents; or for parents either less or more disabled than the norm. In effect, Horowitz's results suggested that when sons assumed the role of carer, there was nothing about the characteristics of their parents which presented any different a caregiving scenario than that faced by daughters. Sons were just as likely as daughters to be co-resident with the parent they cared for, although daughters were more likely than sons to live locally when living separately. Furthermore, there was no significant difference between sons and daughters in terms of the frequency of either telephone or face-to-face contact they had with their aged parent (ibid).

By way of contrast however, Horowitz found that the types and levels of, and time devoted to, care provided by sons and daughters differed substantially. Daughters provided much more "hands on" assistance such as personal care, housework and shopping than sons; tasks which by their nature are time consuming and labour intensive. Only in terms of the management of their parent's financial affairs and dealings with organisations such as social services did sons provide the same level of support as daughters. In terms of the emotional aspects of care, the sons and daughters did not differ in the support they provided to their parents, and Horowitz challenges the assumed femininity of this aspect of care between aged parents and their children (ibid., p615). In terms of caregiving consequences, daughters experienced more strain from caregiving, while more sons than daughters reported that they faced "no problems" in providing care and that they had not given anything up because of caregiving responsibilities (ibid p616). Horowitz explained this in terms of the "women in the middle" syndrome whereby middle aged women are subject to simultaneous and competing demands of home and work, husband, children and elderly parents (Brody, 1981).

Nancy Finley tested the impact of gender on the provision of care to elderly parents via the explanatory power of four variables: time-availability; socialisation /ideology; external resources; and specialisation of tasks (Finley, 1989). Using a random sample of 325 adult children of elderly mothers, Finley found that daughters provided more care than sons regardless of time available, attitudes of kinship obligation, or external resources. Furthermore, her results refuted the notion that men tend to act more as care managers than care providers, and thus she also jettisoned the specialisation of tasks rationale.

Finally here, Spitze and Logan replicated a Canadian research project (Rosenthal et al., 1990) which challenged the hypothesis that caregiving for elderly kin is a normative stressor for middle aged women as suggested by Elaine Brody in 1985. Using a probability sample of 1200 men and women aged 40 or older, Spitze and Logan (1990) examined a variety of kinship and economic roles adopted by middle aged adults. Men were at least as likely as women to be a spouse, a parent, the adult child of an aged parent and an employee. The simultaneous combination of employment, parenting and helping elderly parents however was far less common amongst men than it was amongst women.

By way of conclusion then, the analysis of gender in explaining family care to elderly kin reveals significant differences between sons and daughters according to kinship networks, employment, levels of care provision and effects of caregiving. In other words, the care provided by sons to their elderly parents is both qualitatively and quantitatively different to that provided by daughters. Sons tend to adopt the role of primary carer for an aged parent in the absence of an available daughter, and when they do become carers, the support they offer is less extensive and exerts fewer negative effects than that provided by daughters. What is also clear from the results quoted at length above however is that sons do not necessarily abrogate their filial responsibility. They provide almost as much emotional support and financial assistance as daughters, and are equally as likely to cohabit with an elderly parent. Nevertheless, it cannot be ignored that overall

men contribute just over one third (37%) of all the informal care received by elderly people (Arber and Ginn 1990, p450).

The Study Data

b. Approaching Disaggregation: Sectoral Divisions

After providing an overview of the source of support for each of the 13 ADL and IADL tasks, elderly participants were asked to identify the family member they "relied upon the most". The results are listed in table 4.5 below.

Table 4.5: Elderly Participants' Main Family Carers

N=57 (%)	MAIN CARER
Daughter	16 (28)
Son	10 (18)
Spouse	7 (12)
Other	2 (4)
NO FAMILY CARER	22 (39)

Thirty five elderly people (61%) identified a family member they relied upon "the most" while **22 participants (39%) indicated that they received no family help whatsoever.** This is a notable result. A familiar estimate regarding the quantification of family care is that it accounts for 90 per cent of all care received by elderly people living in the community (Walker ,1982). This is not true of this sample of elderly carers. By way of explanation therefore, it is important to note that domiciliary service users are unrepresentative of the disabled elderly population at large (Evandrou et al., 1986; Arber and Ginn, 1990). Indeed, there is the notion that domiciliary services are distributed via mechanisms independent of levels of functional impairment in order to either reflect carer characteristics or to compensate for the non-availability of family care.

Of those respondents who identified a main family helper, daughters (including daughters-in-law), were the most common source of care. When the 22 respondents who indicated they received no family help whatsoever are excluded, **daughters accounted for almost half (46%) of all the primary family carers identified by respondents.** Equally as interesting however were the numbers of sons accorded primary position in the family caregiving hierarchy by their elderly parent. Although less than a fifth of the elderly respondents in total identified a son as their main family carer, when the 22 respondents who received no family care are excluded, **sons accounted for over a quarter (29%) of all family carers**. Of course, this finding may well be contingent upon an inherent bias in the allocation of domiciliary services towards clients whose family carers are male (Evandrou et al., 1986; Twigg, 1990). Caveat aside however, the finding that sons are a significant source of family care is a notable result.

Nine of the 35 elderly participants who nominated main family helpers were married: of these, seven nominated their spouse as their main family carer. Despite the small numbers involved, this result echoes other research which attests to the primacy of spousal care in the hierarchy of family carers (e.g., Cantor, 1980; Shanas, 1979; Qureshi and Simons, 1987;).

Finally here, the point was made earlier in the chapter that nomination as main family carer did not automatically equate to primary carer status. It is interesting to note therefore that a total of **twenty six (46%) elderly participants replied that they received more help from a non family member than from their own family and of these, twenty one (81%) nominated their home help as their main source of support**. This means that 4 of the 35 elderly participants who nominated a main family helper also replied that this relative was not their primary carer. Such results draw attention to the interaction between formal care and family care at the site of care provision and provide limited to evidence to confirm the thesis that formal services compensate for the non-availability of family care.

In order to reveal the quantitative differences between care provided by different family members, family care was first isolated from formal care. It was decided to exclude four of the 13 ADL and IADL tasks from any further analysis because of the insignificance of family care, indeed any care, received by the elderly participants. These are revealed in tables 4.1. to 4.5 above and were: indoor mobility (only two family carers identified, no formal domiciliary carers and 97% self care); using the toilet (three family carers identified, two home helps and 91% self care); using the telephone (five family carers identified, no formal carer assistance and 91% self care); and getting in/out of bed (six family carers identified, one home help and 88% self care).

The levels of care received for the nine remaining ADL and IADL tasks are ranked in table 4.6 below in terms of the numbers of elderly participants who nominated family care as the most important source of care they received. The first thing to note is that **in terms of cooking, laundry, bathing and getting out of the house, more elderly respondents are self reliant than dependent upon help from others.**

In terms of actual care received however, **elderly participants indicated that they received more support from their families than from domiciliary service workers for all tasks mentioned in table 4.6 with the sole exception of light housework:** dusting and tidying up. This result suggests that from the perspective of elderly care receivers, the primary function of formal services was light housework. Of course, light housework comprises discrete tasks that can be completed within relatively short periods of time, in any order and can be delayed should time constraints prevail: as such, it is ideally suited to highly rationed formal services.

Interpretation of table 4.6 below is helped by knowing that the care receivers were asked to indicate if they received <u>any</u> help at all from others for the relevant task, and who provided them with the <u>most</u> help if they did. The "self" category therefore means that the respondent was totally self reliant and received no help.

By way of corollary however, the "family" and "formal" columns do not necessarily mean that elderly respondents had abandoned all self-sufficiency for the relevant tasks. For instance, in terms of grocery shopping, a not infrequent explanation was that a family member took an elderly participant to the supermarket in their car or accompanied them to the shops. Once at the shop however, the participant made his/her own purchases. In this way then, **the receipt of care identified in table 4.6 actually referred more to the facilitation of a task rather than the transfer of a task from an elderly participant to a carer.** This is not to deny that responsibility did sometimes shift from an elderly person to a carer, but rather to suggest that a clear-cut dichotomy between care receipt and care provision may oversimplify matters:

> I like to do as much as I can. The home help says I'm very independent, but I get downhearted if I had to sit all the time."
> Respondent 123

Table 4.6: The Source of Help Received

N=57 (%)

TASK	SOURCE OF ASSISTANCE		
	FAMILY	FORMAL	SELF
Grocery Shopping	29 (51)	18 (32)	10 (17)
Heavy Housework	28 (49)	18 (32)	11 (19)
Collect Pension/Pay Bill	22 (39)	17 (30)	18 (32)
Prepare Main Meal and Clear Up	20 (35)	14 (25)	23 (40)
Heavy Laundry	18 (32)	15 (26)	24 (42)
Light Laundry	17 (30)	13 (23)	27 (47)
Walk to Bottom of Road	16 (28)	2 (4)	39 (68)
Bath/Shower	12 (21)	11 (19)	34 (60)
Light Housework	11 (19)	39 (68)	7 (12)

c. Disaggregation Within the Family According to Gender

Table 4.7 below is a breakdown of the "family" column denoted in table 4.6 above and identifies the main family carers nominated by the elderly participants for each of the nine ADL and IADL items. For reference purposes, the totals numbers of family carers and their percentages of the total sample (i.e. including formal and self care), are noted under individual ADL and IADL task listing in *italics*. The individual columns exclude all formal and self care and provide a breakdown of the identity of family carers only for each task. It is important to stress here that the conclusions drawn here are tentative because of the small numbers involved.

Four patterns emerge from table 4.7 regarding the character of family care. First, because only nine elderly participants were married, the first column spells out **the predominance of spousal care over all other sources of family care for married elderly people**. Second, and in absolute terms, **daughters were the most common source of family help received by elderly respondents**: the only exceptions were preparing main meals, undertaking light housework and collecting a pension or paying a bill where spousal care was more common. Third, family care was, with very few exceptions, **limited to care provided by adult children and spouses.** Finally, numerical differences aside, **sons were involved with the same range of care activities for their elderly parents as daughters**.

Quantitatively, **differences between care as provided by sons and daughters were particularly pronounced for heavy housework, bathing and helping elderly parents get out of their homes.** Heavy housework, defined as spring cleaning, may well be a mainstay of the efficient and effective "housewife" but it also involves heavy manual work, and thus is one of the principal areas in which sons might be expected to be nominated more frequently. In terms of bathing however, the desire to retain physical privacy and the social mores which accompany that desire, may well have rendered it more acceptable to elderly parents to receive help from daughters than from sons, especially in the case of mother-son dyads. Helping a frail parent to get out of their home on a regular basis

suggests a recognition on the part of the carer of the importance of contact with the wider social world, even if it is simply taking them shopping or to attend a doctor's appointment. The finding that sons were particularly under-represented here implies that the care they provided was limited to instrumental support rather than including any social support and facilitation. Such differences aside however, it cannot be overlooked that **some sons did exactly the same as daughters. These sons bathed their parent, took them out and did their heavy housework:**

Table 4.7: The Disaggregation of Family Help

TASK	CARER Spouse	Daughter	Son	Other	Friend
Grocery Shopping *n=29 (51)*	6 (11)	11 (38)	6 (21)	2 (7)	4 (14)
Heavy H/Work *n=28 (49)*	4 (14)	16 (57)	5 (18)	-	3 (11)
Collect Pension *n=22 (39)*	7 (32)	6 (27)	6 (27)	1	2
Prepare Main Meal and Clear Up *n=20 (35)*	7 (35)	5 (25)	5 (25)	2	1
Heavy Laundry *n=18 (32)*	6 (33)	8 (44)	2	-	2
Light Laundry *n=17 (30)*	6 (35)	7 (41)	2	-	2
Walk to End of Road *n=16 (28)*	3 (19)	8 (50)	2	1	2
Bath/Shower *n=12 (21)*	3 (25)	6 (50)	1	-	2
Light Housework *n=11 (19)*	6 (55)	4 (36)	1	-	-

"He's not that much of a housewife but he'll do a bit. He'll take me out sometimes. He does the messages; he's very good that way."
Respondent 121

> "There are two sons and a daughter left. One of my sons goes into hospital today, for an examination of his heart. My other son helps us (sic) but he's 65. He's retired like, but he has to come and do all my shopping. In fact he comes in on a Wednesday to get my pension book and on a Thursday to do my shopping. It's him that I depend on. I don't get to see my other son that often. My daughter comes in on a Monday and Tuesday lunchtime and has something here (to eat). She works in [town] those days you see." Respondent 126

Table 4.8 below examines the family care received according to the gender of the elderly care receiver. The percentages relate to the numbers of family members identified as carers for each of the 9 tasks rather than to the total sample size. This means that cell sizes are small and conclusions are tentative. The principal observation to be made is that **whereas the main source of family support for elderly men was spousal, elderly women received more assistance from their adult children, especially their adult daughters**. More originally however, table 4.8 reveals that **the range of help received by male elderly participants from adult children was more limited than for female respondents.** Male respondents received no help whatsoever from adult children in terms of getting out of their houses, collecting their pensions and doing any light housework. Furthermore, the level of support they received from their children in terms of shopping for groceries, taking a bath and doing their light laundry was very limited. These findings suggest three possibilities: children provided different supports for elderly mothers as compared to elderly fathers; differences in supports received from children reflected different levels of functional impairment for male and female respondents; and the support provided by formal domiciliary services was differentiated according to service user gender and consequently affected the family care required by elderly people. The first two of these suggestions are examined below; the domiciliary services explanation is explored in chapter 7.

Table 4.8: The Gender of Care Receivers and Family Support

TASK/ GENDER OF RECEIVER	CARER				
n (%)	Spouse	Daughter	Son	Other	Friend
Groceries: 29					
Male: 7	3	-	1	-	3
Female: 22	3	11 (34)	5 (17)	2	1
Heavy Hwork:28					
Male: 8	4 (14)	2	1	-	1
Female: 20	-	14 (50)	4 (14)	-	2
Get Pension: 22					
Male: 5	4 (18)	-	-	-	1
Female: 17	3	6 (27)	6 (27)	1	1
Main Meal: 20					
Male: 8	4 (20)	1	2	-	1
Female: 12	3	4 (20)	3	2	-
Heavy Laundry: 18					
Male:7	4 (22)	2	-	-	1
Female: 11	2	6 (33)	2	-	1
Light Laundry: 17					
Male: 6	4 (24)	1	-	-	1
Female: 11	2	6 (35)	2	-	1
Walk End of Road: 16					
Male: 3	1	-	-	-	2
Female:13	2	8 (50)	2	1	-
Bath/Shower: 12					
Male: 2	1	-	1	-	-
Female:10	2	6 (50)	-	-	2
Light H/work: 11					
Male: 3	3	-	-	-	-
Female: 8	3	4 (36)	1	-	-

The suggestion that the care received by elderly men from adult children differs from that received by elderly women first requires investigation of the gender of family carers identified by the elderly participants. By way of reminder, 35 of the 57 elderly participants identified a family member they "relied upon the most": eight men and 27 women. Whereas elderly men nominated identical proportions of sons and daughters as their main family carer (two each, the remaining men were married and nominated their wives), elderly women were far more likely to nominate daughters as main sources of support than sons: 52 per cent and 30 per cent respectively. Whether this reflects a preferential difference on the part of women or more simply a reflection of the gender of children available is the subject of investigation in the next chapter, which explores the basis of family care.

With reference to any differences in support provided by sons and daughters, table 4.8 above reveals **a predominance of daughters over sons in the provision of all aspects of care**. Despite such under-representation, the range of support provided by sons matched that provided by daughters. For instance, sons shopped and cleaned for their mothers; furthermore, they provided as much help as daughters in terms of helping their mothers to manage their financial affairs (collect a pension, organise the payment of a bill), and in terms of helping both parents to prepare a main meal. These results suggest that **when sons became their parents' main family carers, the scope of assistance they provided was very similar to that provided by daughters.**

The levels of functional impairment of the elderly respondents are also important in describing the similarities and differences between sons and daughters as carers. If we are interested in whether sons and daughters face fundamentally different care scenarios, then care receiver needs again must be accorded centre stage in any analysis.

To recap from the previous chapter, an elderly participant's functional impairment was measured via reference to 13 ADL and IADL tasks. Below, elderly participants' total scores were divided into three groups: between 1 and 4 ("low dependency"); between five and ten ("medium dependency"); and 11 and over ("high dependency"). This means that the "low dependency" group were either unable to conduct two of the tasks or had difficulty with up to four tasks; the "medium dependency" group were either unable to conduct five tasks or had difficulty with up to ten tasks; while the "high dependency" group were unable to conduct more than five tasks or had difficulty with more than ten tasks.

Table 4.9 below catalogues the nine tasks for which family care figured most prominently according to the dependency levels of the care receivers and the main insight it provides is that family care for elderly kin was consistent with high levels of dependency. With the exception of heavy housework **at least three quarters of elderly respondents who nominated a family member as their primary carer for each of the relevant nine tasks had "high" dependency levels.** Family care was received by elderly participants with "low" dependency levels when the task involved demanded physical effort such as heavy housework and grocery shopping. By way of contrast, and in support of previous conclusions drawn about personal care received by the respondents, family help with taking a bath or having a shower occurred only at "high" levels of dependency.

Table 4.9: The Scope of Family Care Received As Distinguished by Dependency Level

FAMILY CARER TASK	DEPENDENCY LEVEL		
n (%)	Low	Medium	High
Grocery Shopping: 29	3 (10)	4 (14)	22 (76)
Heavy H/work: 28	5 (18)	4 (14)	19 (68)
Pension/Bill: 22	-	3 (14)	19 (86)
Main Meal: 20	2	2	16 (80)
Heavy Laundry: 18	1	1	16 (94)
Light Laundry: 17	1	-	16 (94)
Walk To End Of Road: 16	1	2	13 (82)
Bath/Shower: 12	-	-	12 (100)
Light Housework: 11	-	1	10 (91)

In order to highlight any differences between the care scenarios faced by daughters and sons, we also need to isolate the relevant care receivers' dependency levels. This reduces the numbers involved but nevertheless provides an indication of any differences here. **For grocery shopping, heavy housework, and preparing main meals, the dependency levels of elderly participants supported by daughters were higher than those supported by sons.** Almost three quarters (73%) of elderly respondents who identified their daughters as their main carer for shopping had "high" dependency levels: this compares with 50 per cent of those who identified their sons. For help with collecting pensions or paying bills, walking to the bottom of the road, having a bath or shower and light housework, there was no difference between the dependency levels of parents helped by daughters as compared with sons. Finally, **for light and heavy laundry, elderly participants supported by sons had higher levels of dependency than those supported by daughters.**

Summary and Conclusions

The discussion in this chapter has concentrated upon the main sources of help identified by elderly participants and has discussed how objectively identified care needs differed from subjective definitions of need. Very importantly, the results revealed a number of differences between the relative contributions of support provided by family members and domiciliary workers. While family care predominated over formal care in general terms, such predominance was neither uniform nor unequivocal across different care tasks. In particular, elderly participants indicated that domiciliary support was more important than family support for light housework; 78 per cent of the 50 elderly participants who stated that they any received help at all with light housework indicated that home helps were their main helpers. In other areas, such as having a bath or shower, light and heavy laundry and collecting pension, while assistance from relatives was more common than domiciliary support, the margin of difference was slim. Indeed, the only areas where elderly participants indicated that family help clearly predominated in magnitude over domiciliary support were: heavy housework (61% of elderly participants who indicated they received *any* help stated that a family member was the most important source of help); assistance with walking down the road (although a major care gap was also identified here); grocery shopping (62% of all participants who received any help pointed towards a relative as their most important helper); and indoor mobility (although very low levels of support were revealed by participants here).

Overall, these results translated into a script in which 39 per cent of all elderly participants stated that they received no support whatsoever from any family member: Of the remaining 35 participants, just under half nominated a daughter as their main family carer and just over a quarter indicated that a son was their main family helper. Whether this low level of family support reflects truncated family networks is addressed in the chapter six; at this point in the argument however such results are clearly reminiscent of research which contends that domiciliary

services are allocated in ways deliberately designed to compensate for the absence, rather than to support the presence, of family carers.

The chapter also included a simple breakdown of tasks provided by the 35 relatives nominated by the elderly participants. The results echoed other research which points towards the primacy of spousal care but also suggested that when sons assume the "main carer" mantle, they provide the same range of supports as their sisters. Finally, this chapter has revealed a number of significant gaps; gaps defined in terms of elderly participant's clear specification that they required more help with certain personal care and household management tasks and gaps which neither family care nor domiciliary services filled in either isolation or combination.

5

EXPLORING THE BASIS OF FAMILY CARE

Introduction

The significance of the dynamics of family care is founded upon the observation that family care for elderly kin represents an important example of how families behave as formal social systems (Shanas 1979; Cantor 1979; Finch 1989; Qureshi and Walker 1989). Such "dynamics" emphasise the biographical, affective and normative roots of care provision. For instance, family care is affected by the direction and strength of the relationship between the concepts of responsibility and obligation held by both caregiver and care-receiver, (Firth, Hubert and Forge, 1970). Furthermore, it is underpinned by emotional bonds between care-receiver and family carer; bonds which secure an alleged superiority and preferred status over formal care services (Graham, 1983). In other words, family care of elderly kin is shaped by the mutual expectations of one generation upon the other; the desire and ability of each to uphold such expectations; and the emotions that exist between them. Any attempt to explain the organisation of family care therefore must refer to the content, contours and context of the family network and the system of values, expectations, and notions of obligations that network describes (Townsend, 1957; Shanas, E. et al., 1968; Finch, 1989; 1990).

This chapter looks towards the structural, affectual and attitudinal characteristics and values which form the foundations and motives for filial care. It is concerned to identify the relational and structural antecedents which impact upon the organisation of filial care to aged parents. The chapter is based upon an extensive review of the caregiving literature and reflects the consensus contained therein that the dominant characteristics of the dynamics of family care pertain to: family

structure; the different roles and responsibilities held by aged parents and adult children; parent-child interaction in terms of contact patterns, exchange, assistance and support; and the quality of relationship that exists between the aged parent and their middle aged child. Details regarding exchange, assistance and support patterns between aged parents and their adult children were discussed previously while this chapter presents the relevant data on structure, contact, affect and beliefs. The chapter assesses each of these antecedents of care separately although it is likely to be their cumulative effect which determines the identity of a family carer and the quality and content of the caring relationship.

Social Solidarity and the Family System

The social system analogy of the family forces attention onto constructs such as socialisation, interdependence, maintenance of equilibrium and attainment of goals: in other words, how and why families function in the ways they do. Such issues are, of course, at the very core of classical sociology, and provide the basis for the proposed model of the conceptualisation of the dynamics of family care to aged parents: social solidarity.

The notion of social solidarity finds its roots in the work of Emile Durkheim (1933). His grand theory of mechanical and organic solidarity corresponds to the different types of social relationships identified in pre-industrial and industrial societies respectively. Mechanical solidarity describes normative cohesion by means of traditional norms and customs. In mechanical society for instance, because of a "common conscience" (Durkheim, 1933, p63), individuals are interchangeable in function. Organic solidarity on the other hand relates to industrial society in which the division of labour is a key feature. Organic solidarity thereby highlights the functional interdependency of all individuals and provides the basis of societal solidarity via the complementarity of roles different individuals adopt.

In similar mode, Ferdinand Tonnies's (1957) codification of social relationships is based upon the observation that stronger bonds develop between people when they are accompanied by normatively prescribed obligations, such as those which exist among family members. Tonnies compares very cohesive (Gemeinschaft) social relations characterised by obligation, with the less cohesive (Gesellschaft) relationships characterised by a consensus over the operation of reciprocity. Both Durkheim and Tonnies conclude that interpersonal normative commitment and obligation are the key antecedents to high levels of social solidarity (Roberts et al., 1991 p14).

The major weakness of the organic/mechanical and Gemeinschaft/Gesellschaft dichotomies of course resides in their alleged mutual exclusion. A major conclusion of Weber (1968) and Parsons (1951) is that the twin foundations of solidarity operate simultaneously, and that solidarity therefore comprises normative prescriptions, functional interdependence, and consensus over rules of reciprocity. In other words, mechanical aspects of solidarity exist simultaneously with organic aspects. For Weber and Parsons functional interdependence (rooted in organic solidarity), is vital to the continuation of any social system and this interdependence is, in turn, a key feature of the school of structural functionalism. Parsons based his notion of functional integration primarily on Durkheim's organic solidarity and applied it to the family and the socialisation of children. In terms of family solidarity, Parsons found that the instrumental support of physical needs, and the affectual support of emotional needs are additional characteristics of the operation of functional interdependence in sustaining the family unit (ibid).

The purpose of this whirlwind introduction to classical sociology and structural functionalism is to emphasise the relevance of family solidarity to family care. Family solidarity provides a comprehensive guide to the maze of routes via which families operate as cohesive groups: it travels via family structure, the ways in which families interact, the values and sense of obligation which belie that interaction, and the emotional commitment that exists between family members.

In addition to classical sociology however, social psychology (e.g., Homans, 1959 and 1961) and family studies (Nye and Rushing, 1969), have also informed the conceptual development of family solidarity. Furthermore it is important to realise that in methodological terms, the operationalisation and measurement of family solidarity is still amenable to refinement and improvement (McChesney and Bengtson, 1988 p27).

The family sociologists Nye and Rushing (1969, p135) deal with family solidarity as a multidimensional construct containing six components: **associational integration** (the range and frequency of interaction in different types of activities); **affectual integration** (the amount of positive sentiment held between family members); **consensual integration** (agreement upon values, attitudes and beliefs); **functional integration** (instrumental support and exchange); **normative integration** (the degree to which family members conform to family norms); and **goal integration** (the degree to which family members subordinate individual goals to those of the family).

In operationalising their taxonomy, Nye and Rushing identify associational integration, affectual integration and consensual integration as higher order concepts which impact upon functional, normative and goal integration. Nye and Rushing's model is thus reminiscent of Durkheim's mechanical mode of solidarity because of its concern with shared activities, norms and beliefs; a feature which persists in more contemporary work in the area of family solidarity. Bengtson and Schrader (1982, p116) conceptualise family solidarity in a very similar fashion to Nye and Rushing but substitute "intergenerational family structure", recording the number, type and propinquity of family members, for the Nye and Rushing "goal integration" category.

The model of family solidarity developed by Bengtson and his colleagues (1985) describes the variety of vertical bonds which exist in families containing aged parents: intergenerational contact; feelings towards each other; assistance, and expectations. Most important however, they present family solidarity as the

construct which controls the provision of family care to elderly kin. Family care is seen to both arise from, and impact upon, family relationships, and thereby focuses attention upon experiences of providing and receiving care. In other words, examination of family solidarity provides direct access to an analysis of the dynamics of family caregiving.

Family solidarity is a suitable vehicle for research seeking to capture the dynamics of family care: it stresses similarities between family members (but also allows room for analysis of the complementarity of roles between different family members), the interdependence of different family members and the commonality of goals. Furthermore, the family solidarity perspective allows for both the provision and receipt of family care for elderly kin to be included within a single systems approach.

Specifically, this chapter examines four sets of constructs thought to influence the organisation of care adult children provide frail aged parents: family structure; parent-child contact; the quality of the parent-child relationship; and opinions concerning the normative obligations of adult children to care for their elderly kin.

1. The Significance of Family Structure for Family Care

Demographic ageing and the sociological, economic and geographical transformation of the family have all fuelled debate about the respective roles and responsibilities that exist between elderly people and their families. In particular, increased longevity accompanied by decreased fertility and increased marital breakdown are trends thought to compromise the potential supply of family carers at a time when the need for care continues to grow. Such changes in family structure, exacerbated by women's changing socio-economic status, have engendered the "moral panic" surrounding the debate on intergenerational transfers (Arber and Ginn ,1991 p263).

Research on elderly people and their families also contains elements of this "panic", especially when it is driven by concerns about the extent to which elderly people are alienated or abandoned by their families. Social gerontologists of course have been very successful in challenging the "social myth" (Shanas, 1979) of the isolated nuclear family in which patterns of intergenerational exchange diminish over time (Townsend, 1965; Shanas, 1979; Qureshi and Walker, 1989; Rossi and Rossi, 1990). Indeed, research demonstrates that the salience of intergenerational bonds has grown over time as greater longevity increases the "cobiography" of aged parents and adult children (Hagestad, 1987).

The effect of these demographic and economic transformations has been to focus attention squarely upon the family structures of elderly people and their relations with younger kin. Family structure records the number, sex, age and propinquity of family members. It is recognised as a key determinant of both intergenerational relationships and the social support the family provides elderly kin (Shanas, 1979; Townsend, 1968). More recently, family structure has been regarded as especially important in the formulation of a carer hierarchy and in the prediction of which family member will become an elderly person's "primary carer" (Cantor, 1979; Qureshi and Simons, 1987).

For instance, marital status represents the most obvious and important horizontal family relationship, and although it is fair to say that marital relations in the later stages of life have attracted relatively little attention in academic research[1] the fact that a husband or a wife occupies the top echelon in the hierarchy of caregiver "selection" is well established (Qureshi and Simons, 1987; Arber and Gilbert, 1989; Finch, 1989). Next in the hierarchy, the presence of children, especially that of daughters, is seen as a reliable proxy measure of the potential receipt of family support by elderly people. Sons follow next. The effect of grandchildren, and indeed great-grandchildren, upon family care is potentially contradictory. If still dependent, (great) grandchildren can not be added to the list of potential carers and

[1] An important publication, edited by Sara Arber and Jay Ginn, provides an important development in this area, e.g.: Gail Wilson (1995) "I'm the eyes and she's the arms".

may frustrate the caregiving activities of their parent(s). If sufficiently mature however, they may very well offer significant additional support to a frail grandparent.

The degree to which siblings can be called upon to provide support in old age represents a new field of inquiry as almost nothing is known about the trajectory of sibling relationships over time (Gold ,1989 p20). Research is now beginning to examine the sibling relationship according to the support that aged sisters and brothers provide each other (see Brubaker, 1990), and although the levels of association between siblings are lower than those which exist between parents and children (Cicirelli, 1982), the significance of sibling support during old age is likely to increase in the future as the numbers of adult children available to frail elderly people diminish.

The number of adult children elderly people have is important because it provides an indication of the potential number of carers available to them (McChesney and Mangen , 1988 p58). The gender of children is significant because of the well acknowledged feminine specificity of family care (Brody, 1981; Dalley, 1988; Finch and Groves, 1983; Graham, 1983; Land, 1978) and because intergenerational cohesion and exchange within the family is most usually facilitated through female members (Brody, 1981; Shanas, 1979b; Townsend, 1957). The ages of an elderly person's children are also relevant because research suggests that adult children whose own children are no longer dependent and who have left home have more resources to become carers in terms of both time and money (McChesney and Mangen, 1988). Furthermore, when adult children are themselves "aged", they are increasingly susceptible to chronic, debilitating, health complaints. Finally, the propinquity of an adult child to their elderly parent affects whether they are likely to be at all implicated in the provision of care to their parent (Shanas, 1979b).

The Study Data

Filial Structure and Propinquity

The information collected about family structure is limited to the elderly participants' adult children because the focus of interest is filial care. The elderly participants were asked to provide full details about the identity and location of each of their children.

Table 5.1 below reveals that **50 (88%) elderly participants had children: indeed between them, the participants had a total of over one hundred (103) children.** It should be noted here that the coding format on the questionnaires allowed for details to be recorded for participants' oldest four children only, and this means that the details of five children are omitted. Of the 98 children recorded in Table 5.1 then, the slim majority **(55%) were daughters, the very large majority were middle aged (92%), and 45% lived within half an hour's journey of their parents' home**, (including those nine adult children who lived with their parents), **although 47% also lived an hour or more from their parents.**

The practical care required by elderly people with medium to high levels of functional impairment is regular, repetitive, and routinised and any filial carers need to live in fairly close proximity. With the practical difficulties imposed by long distance then, parents admit that their contact with children who lived more than an hour's journey away was occasional: as such, these children avoided implication in their parents' care and practical support:

> It can't be more than every ten years that she comes over (*from New Zealand*); it'll be a long time before I see her again.
> Respondent 137

> I couldn't do without them now (*respondent has 6 children*). None of them stay at home of course. But I only get to see David (*the one child no longer living in Scotland*) once in a blue moon.
> Respondent 142

By way of corollary however, 45 per cent of the participants' children lived within half an hour of their parents. Ignoring all other constraints, these children were "on hand". In the case of an emergency, they were better placed than their distant siblings to reach their parents promptly and were more likely to be implicated in the provision of their parents' regularly required supports:

> Every day she comes round to do anything she can. I have one home help once a week. The rest of the time (*daughter*) does it.
> Respondent 138

> They come every week. Duncan (son) brings my pension.... Occasionally he might look in on a Saturday or Sunday but he likes his fishing and that. I get to see (other son) a wee bit more; perhaps on a Tuesday and a Thursday and then again on the weekend.
> Respondent 135

Table 5.1: An Introductory Profile of the Participants' Children

	TOTAL CHILDREN n=98 (%)		
Sons	44 (45)	**Sons**	**Daughters**
Daughters	54 (55)	n = 44 (%)	n = 54 (%)
Age: Under 40	4 (4)	1 (2)	3 (6)
40 - 54	60 (61)	27 (61)	33 (61)
55 - 64	30 (31)	12 (27)	18 (33)
65 and over	4 (4)	4 (9)	-
Journey Time from Parent:[1] same household	9 (9)	6 (13)	3 (6)
Under 10 minutes	9 (9)	2 (5)	7 (13)
10 to 30 minutes	26 (27)	12 (27)	14 (26)
31 to 60 minutes	8 (8)	3 (7)	5 (9)
Over hour- under day	32 (33)	13 (30)	19 (35)
Day and over	14 (14)	8 (18)	6 (11)

[1] This propinquity scale was developed by Ethel Shanas (1979b) and reflects how time consuming, and thus how difficult, a visit to an elderly parent might be.

Finally, table 5.1 serves to demonstrate the similarity between respondents' sons and daughters in terms of age and propinquity to their aged parent. Eighty seven per cent **(87%) of sons and 94 per cent of daughters were aged between 40 and 64: while 45 per cent of both sons and daughters lived within half an hour's journey of their parents' homes.** This means that any differences between sons and daughters with regard to the care they furnished for their aged parents reflected factors other than geographical proximity and age.

Table 5.2 below addresses the home and economic circumstances of the respondents' children in terms of marital status, employment and children of their own. It should be noted that a fluctuating number of cases are missing for each of the three variables: this occurred because I came across instances where all communication between elderly participants and particular children had ceased. This meant that the elderly participants involved were unable to provide relevant details about these adult children. In some instances, the circumstances which accounted for this breakdown were shocking and served to emphasise the point that family care is sometimes the very worst care option for elderly people:

> My son could charm the birds out of the tree; he's the biggest liar out. I'm better off without him; that way I don't have to worry about him...He beat me up one Christmas: he pushed me all the way down the stair *(sic)* and hit me about something terrible. That was the last time I saw him; five years past December.
> Respondent 134

> I have one son but I have nothing to do with him. He's turned on me twice now. Once he almost strangled me; his second wife had to pull him off. That's why I got the phone in; for security.
> Respondent 119

The first point of interest in table 5.2 is that **the great majority of respondents' children were married, (83%)**, and thus had the needs of their spouse to consider as well as those of a frail elderly parent: a key feature of the "women in the middle" syndrome. Next, **the slim majority of adult children were in employment, (55%)**, meaning that any time they devoted to their parents' care was circumscribed by their working hours. Finally, **over three quarters (77%) of**

the adult children had children of their own: and while the great majority of these, (79%), were aged 17 or over, a fifth had younger children who can be classified as a "dependent" and who were therefore likely to make the first demands upon their parents' priorities.

Table 5.2: Marriage, Children and Employment:

An Overview of Elderly Participants' Adult Children

* cases missing	**TOTAL N=98 (%)**	Sons n=44	Daughters n=54
Married: Yes	81 (83)*	34 (77)	47 (87)
No	16 (16)*	9 (20)	7 (13)
Employed: Yes	54 (55)*	27 (61)	27 (50)
No	41 (19)	16 (36)	25 (46)
Children: Yes	75 (77)*	32 (73)	43 (80)
No	19 (19)	8 (18)	11 (20)
Age of Youngest Child: Under 5	n=75 1 (1)	1 (2)	-
5 - 16	14 (19)	8 (18)	6 (11)
17 - 25	30 (40)	11 (25)	19 (35)
25+	29 (39)	12 (27)	17 (31)

Table 5.2 illustrates that **a higher proportion of daughters than sons were married with children, although a higher proportion of sons were in employment.** Spouses, children and employment all limit the potential amount of time available to a family carer and may oblige him or her to make hard choices among their competing obligations. Elderly participants were aware of these competing priorities, and articulated an acceptance that their own care needs did not assume primary importance for their adult children:

> Oh, I'm well looked after by my family, hen. We're a family that's all together. It's just the shifts *(one son work shifts)* and the shop (*another son runs his own shop*) that stops us seeing more of each other... Of course, *(son's)*, wife is very good, but since she's had her arthritis she cannae do very much for me. And (*other son's)* wife does all the shifts at (*her place of work*). So I lean on the two boys the most.
> Respondent 144

> They're all working; they all do different shifts. They've got their own families and their men and their homes.
> Respondent 109

In order to evaluate the impact of family structure on the actual provision of family care, a number of characteristics of adult child carers were taken into account. Of particular interest was the impact of family structure upon the propensity of sons (as opposed to daughters) being identified by the participants as their main family carers.

We already know that 16 elderly participants nominated daughters while ten nominated sons as their main family carers. Table 5.3 examines these sons and daughters in detail and first reveals that the 26 elderly participants had a total of 63 children. The small cell sizes, table 5.3 confirms existing research: it highlights the importance of the gender profile of all children in a family in the determination of a main adult child carer for elderly parents. Specifically, **where the main family carer was a son, the total number of sons exceeded that of daughters by a factor of more than three. Where the main family carer was a daughter, they also outnumbered sons but by a factor of less than two.** In other words, sons were the main filial carers for their elderly parents in families in which there were fewer daughters, both absolutely and relatively. This supports the conclusion that sons become carers for their elderly parents in the absence of daughters.

Another result revealed in table 5.3 concerned an apparent gender difference in coresidence with aged parents. **Twenty per cent of all filial carer sons resided with their elderly parent in comparison to 8% of the carer daughters.** In only one case was the coresident child not also the nominated main family carer; a son living with his widowed mother who nominated her two local daughters as her

main family carers. When sons were nominated as primary family carers by their elderly parents therefore, they were far more likely than daughters to be resident with their aged parents. The research did not investigate the duration of coresidence nor whether coresidence preceded or followed the start of care provision and thus we do not know from the data here whether coresidence was a cause or a consequence of sons' caregiving activities.

Table 5.3: A Profile of the 26 Filial Carers

All children n=63 (%)	Main Family Sons (n=10)	Carer Daughters (n=16)
Total Children in Family:	n=25 (%)	n= 38 (%)
Male	19 (76)	13 (34)
Female	6 (24)	25 (66)
Time away from parents' home:		
Same household	5 (20)	3 (8)
under 10 minutes	3 (12)	5 (13)
10 to 30 minutes	8 (32)	14 (37)
31 to 60 minutes	1 (4)	4 (11)
Over an hour less than a day	5 (20)	8 (21)
Day and over	3 (12)	4 (11)

Coresidence aside however, **44 per cent of all the children of elderly people whose main carer was a son lived within half an hour. This compares to 61 per cent of children of the elderly parents whose main carers were daughters.** In other words, when daughters were nominated as their parents' main family carers, they had more proximate siblings than son carers. This result provides further support to the hypothesis that sons become carers in the absence of other available children.

Because it is supposed that the absence of children, and especially the absence of daughters, corresponds with a lack of family care (e.g., Spitze and Logan, 1990),

Table 5.4 examines filial structure when elderly participants indicated that they received no family care. Thirty nine per cent (39%) of all elderly participants stated that they did not receive any family help., the large majority of whom (77%), had children: in fact, they had a total of 24 children between them.

Table 5.4 below provides a clear insight as to why these sons and daughters failed to provide parent care: propinquity. **Three quarters of these 24 children lived an hour or more away from their parents: too far to be their parents' daily carers.** Of course, the numbers involved here are again small, but it is interesting to note that three daughters lived within half an hour of their parent and yet failed to provide their parent with any help whatsoever. The proximity of daughters to elderly parents is thus not a perfect correlate of filial care provision.

Table 5.4: The Propinquity of Children of Elderly Parents In Receipt of No Family Care

	Sons n=6	Daughters n=18	Total N=24 (%)
Time away from parents' home:			
Same household	-	-	-
under 10 minutes	-	1	1 (4)
10 to 30 minutes	-	2	2 (8)
31 to 60 minutes	2	1	3 (12)
Over an hour less than a day	4	11	15 (63)
Day and over	-	3	3 (12)

2. Contact Between Elderly People and their Adult Children and Family Care

The importance of propinquity in the provision of filial care to elderly kin provides an appropriate introduction to the next antecedent to understanding the dynamics of family care: contact between adult children and their aged parents.

Previous research in this area provides compelling evidence of high levels of contact between the elderly and their children (Townsend, 1965; Shanas, 1979; Bengtson et. al., 1985; Qureshi and Walker, 1989; Rossi and Rossi, 1990). In fact, elderly people prefer to live near, rather than with, their children in order to ensure that they see them regularly; a phenomenon termed "intimacy at a distance" (Townsend, 1957; Rosenmayer and Kockeis, 1963). Furthermore, elderly people may well act as a practical and financial resource to their adult children (Cantor, 1979; Cicirelli, 1981).

In the context of family care, the significance of contact between elderly people and their adult children can be simply stated: the more contact the two parties have, the more opportunities and reasons they have for family care to take place. The rationale for this statement is that care needs are likely to be better understood and responded to when aged parents and their adult children are in regular and sustained contact. The importance of propinquity in predicting the frequency of visits between elderly people and their children is well established in the literature (e.g., Shanas et al., 1968). In fact, propinquity has been identified as the single most important predictor of association between aged parents and their adult children (Bengtson et al., 1976). Propinquity aside however, the degree of association between elderly people and their children varies between families and is far from uniform amongst chronologically similar family types.

Four factors of social differentiation are **thought** to be of significance: gender; marital status; social class; and ethnicity. Married daughters tend to have closer ties to their aged parents than married sons (Stoller, 1983; Wright, 1983). This is especially so when the parent is a widowed mother; evidence suggests that they tend to regard daughters as sources of emotional support and sons as sources of instrumental support (Treas and Bengtson, 1987 p635). Furthermore, both widowed elderly people and single adult children are more likely to have stronger associational ties than their married counterparts (Treas and Bengtson, 1987). Results in terms of social class are highly equivocal. Basically, while previous research reveals that working class children are more likely to be in closer contact

with their aged parents than middle class children (Cantor, 1975), it has been suggested that the direction of a child's social mobility would confound this principle (Brody, 1990). Finally, the effect of ethnicity upon levels of association between aged parents and adult children is still far from clear, and further research is a fundamental requirement, (Thomas, 1993).

The Study Data

Levels of Contact Between Elderly Parents and their Adult Children

Three forms of contact between elderly respondents and their adult children were measured: face to face contact; telephone contact; and written contact. Analysis was again limited to elderly participants' oldest four children. Finally, because of its significance for aged parent-adult child contact, it is worth recalling the main results about the geographical proximity of children to their aged parents: while 45 per cent of the respondents' children lived within half an hour of their parent, a greater 47 per cent lived an hour or more away.

This last measure perhaps helps explain why elderly participants reported that they saw the majority of their children (60%) once a month or less. Excluding those children who resided with their aged parents, **only 16 per cent saw their parents either daily or a few times a week.** These results have very obvious implications for the sorts of care children are likely to have provided elderly participants. At the very least, infrequent contact complicates the delivery of multiple repetitive tasks the elderly participants required on a regular, if not daily, basis. The finding that relatively few children saw their elderly parents several times a week however did not mean that the levels of other forms of intergenerational contact were low. In particular, **over half (57%) spoke to their parents on the telephone at least once a week or more.** Letter writing was of negligible importance in terms of contact between elderly participants and their adult children; 72% of children wrote only at Christmas, birthdays or anniversaries. The frequency of telephone

contact however affirmed the durability and importance of the adult child-aged parent relationship.

Table 5.5: Contact between Elderly Participants and their Adult Children

CONTACT TYPE	Sons n=44 (%)	Daughters n=54 (%)	Total N=98 (%)
Face to face: Same household	6 (14)	3 (6)	9 (9)
Daily	1 (2)	5 (9)	6 (6)
Few Times Week	4 (9)	6 (11)	10 (10)
Weekly	8 (18)	6 (11)	14 (14)
Monthly	3 (7)	8 (15)	11 (11)
3 or 4 times year	4 (9)	9 (17)	13 (13)
Less than every 6 months	18 (41)	17 (31)	35 (36)
Telephone: Same household	6 (14)	3 (6)	9 (9)
Daily	-	5 (9)	5 (5)
Few Times Week	4 (9)	13 (24)	17 (17)
Weekly	17 (39)	17 (31)	34 (35)
Monthly	6 (14)	8 (15)	14 (14)
3 or 4 times year	4 (9)	5 (9)	9 (9)
Less than every 6 months	7 (16)	3 (6)	10 (10)
Write:			
Same household	6 (14)	3 (6)	9 (9)
Monthly or more	2 (4)	3 (6)	5 (5)
Few times year	3 (7)	4 (7)	7 (7)
Birthdays/Xmas	29 (66)	42 (78)	71 (72)
Never	4 (9)	2 (4)	6 (6)

With regard to any gender differences in association between aged parents and their children, table 5.5 also illustrates that **31 per cent of non coresident daughters and 29 per cent of non coresident sons saw their aged parent once a week or more.** It is important to recall that 48 per cent of daughters and 39 per cent of sons lived within one hour of their parent. Thus even though sons tend to have longer distances to travel to see their parents than do daughters, the frequency

of their visits was not reduced by an equivalent factor. The main gender difference exists in terms of telephone contact: 64 per cent of daughters, in comparison with 48 per cent of sons, spoke to their parents at least once a week. Whether this difference reflected closer emotional ties between daughters and their elderly parents than is the case with sons is examined in the section on affect below. At this point however it would seem that although sons spoke to their parents on the telephone less frequently than daughters, when propinquity was standardised, their levels of face to face contact with their parents was very similar.

The prevailing orthodoxy in family care research is that daughters provide larger amounts and more varied kinds of assistance to their parents than sons (e.g., Brody and Schoonover, 1986; Litwak, 1985). As such, daughters devote far more time than sons in caring for aged parents (Horowitz ,1985). In terms of the levels of contact between adult children and aged parents reported here however, there appeared to be more similarities than differences between sons and daughters.

3. The Significance of Affect between Elderly People and their Adult Children

The antecedent to family care being explored under this heading is that care for one's aged parents epitomises an enactment of friendship and filial love. The importance of this aspect of care is eloquently expressed by Hilary Graham and her thoughts are worth quoting in detail:

> Stripped of the emotional bonds which encompass it, caring becomes redefined as "tending", "the actual work of looking after those who, temporarily or permanently cannot do so for themselves"...But caring is more than this: a kind of domestic labour performed on people. It can't be "cleaned up" into such categories without draining the relationship between carer and cared-for of the dimensions we most need to confront. Caring cannot be understood objectively and abstractly, but only as a subjective experience in which we are all, for better or worse, involved.
> Graham 1983 pp27-8.

The quality of the relationship between adult children and their aged parents concerns notions such as closeness, warmth, and satisfaction with interaction. It has been described as: "mutual positive sentiment among group members and their

expressions of love, respect, appreciation, and recognition of others." (Bengtson and Schrader, 1982 p118). Difficult to operationalise, the measurement of affect between aged parents and their adult children is a relatively under-investigated area (Gold, 1989; Gronvold, 1988 p95). The evidence available suggests that levels of affect are high (Brody, 1981; Bengtson and Treas, 1980) although they are susceptible to change over time. Furthermore, affect levels tend to decrease as the health related needs of the elderly parent increase (Rossi and Rossi, 1990).

Interestingly, research has found that aged parents attribute higher levels of affect to their relationship with their children than do the children themselves. This may be explained via the "generational stake theory" (Bengtson and Kuypers, 1971): a theory which states that aged parents attribute more importance to their relationships with their adult children than vice versa because aged parents' goals and ambitions are very much bound up with their children and grandchildren whilst adult children have superseding goals which place their own families, and possibly careers, above their concerns for their aged parents. Thus children who "love" their aged parents often face ethical dilemmas regarding the limits of sacrifice their love permits; a feature of intergenerational relations which has been so effectively researched by Elaine Brody and colleagues.

The most interesting aspect of the relationship between affect and care is the twist in the tail; its potential for inversion over time. Whilst affect between aged parents and their adult children provides a motive for family care, the relentless, intensive and physically demanding nature of such care means that its very provision often provokes feelings of burden and stress (Braithwaite, 1990). Indeed, the multiplicity of identifiable "costs" associated with the provision of family care provides a major focus within the caregiving literature (Parker, 1990 p57; Rimmer, 1983; Abel, 1987; Equal Opportunities Commission, 1982; Joshi, 1987; Glendinning, 1992). Over time, these "costs" act to distort the original feeling of affect between the aged parent and their adult children; positive sentiment is replaced by exhaustion, frustration, resentment and even anger. The caring relationship between adult children and aged parents is particularly susceptible to

such affectual distortion because of the combination of "five crises" peculiar to the care of elderly relatives: degeneration; unpredictability; time constraints; restrictions of choice; and the carer-carereceiver relationship (Braithwaite, 1990, p8). By way of brief paraphrase, elderly parents hardly ever "get better" or become less needy of care. Rather, their physical and/or cognitive decline advances at an unpredictable rate, meaning that the inevitable increase in amounts of care required over time is incalculable. This leaves the carer with less and less time to do other things and an accompanying sense of frustration because the elderly person does not improve no matter how much effort or devotion is applied. The end result is a diminution or distortion of the original sentiment that provided the catalyst to care: affect.

The Study Data

Levels of Affect Between Elderly Parents and their Adult Children

The measurement of affect between elderly parents and their adult children is an under-investigated area and the availability of measurement scales for guidance on this matter is very limited (see Gronvold, 1988). A decision was taken therefore to examine both positive and negative affectual aspects of the relationship between elderly participants and their adult children because of the research quoted above that demonstrates how the emotion underpinning family care can be simultaneously positive and negative. Emotional closeness is a thus one component of the affectual scale, as is trust and consideration. On the negative side however, the provision of care may evoke criticism and even resentment.

The affectual scale comprised four questions: how often a child made an elderly participant feel loved and cared for; how much a child was willing to listen when the participant needed to talk about his/her worries; how critical a child was about a participant; and how often a child made too many demands on a participant. A five point response scale was used: 1. not at all; 2. a little; 3. occasionally; 4. quite a bit; and 5. a great deal.

It should be noted that the total number of children denoted in table 5.6 below is 96: two short of the total number of children detailed in the questionnaires. Basically, two of the three proxy interviews conducted were excluded because the adult child answering on their parent's behalf would have been asked inappropriate questions which would have required them to either criticise or praise themselves.

Table 5.6: Levels of Affect between Elderly Participants and their Children

N=96 (%)

	Not at all	A Little	Occasionally	Quite a Bit	A Great Deal
Children make you feel loved and cared for	12 (13)	3 (3)	14 (15)	30 (31)	37 (38)
How much Children listen	13 (14)	10 (10)	17 (18)	18 (19)	38 (40)
How much Children Criticise	54 (56)	21 (22)	11 (11)	3 (3)	6 (6)
How often children make too many demands	85 (89)	6 (6)	2 (2)	2 (2)	1 (1)

Table 5.6 reveals that the elderly respondents generally attribute high levels of affect to their relationships with their children. **Sixty nine per cent (69%) of the elderly participants' children were reported as making their parents feel loved and cared for either "quite a bit" or "a great deal". Furthermore, 59 per cent listened to their aged parents "quite a bit" or "a great deal"** when their parents need to talk about their worries or problems. By way of contrast, **a much fewer 9 per cent of the participants' children were reported as consistently critical, while only 3 per cent were considered by their aged parents as being too demanding.**

Despite the general high levels of positive affect reported it is important not to overlook those participants who reported very low levels of affect with their children. In all, **13 per cent of children were reported as not making their parent feel loved or cared for at all, whilst almost a quarter (24%) purportedly hardly ever listened or never listened when their parents needed someone to talk to** about their problems or worries. These results serve to emphasise that the emotional bonds which help render family care preferable and superior to formal care are not infallible: some elderly people simply did not have a loving and caring relationship with their children and were probably better served by formal service workers.

In a final and more open ended question designed to probe the degree of affect between elderly participants and their families, respondents were asked to evaluate whether the family help they received brought them any closer to their carer(s), made relations more difficult with their carer(s), or simply did not affect the quality of their relationship with their carer(s). The results here were equivocal. Of the 35 respondents who received family care, just over half (51%) said that their receipt of family care had resulted in a closer relationship with their family carer. By way of contrast however, another ten elderly participants (29%) replied that their receipt of filial care had been accompanied by a deterioration in the relationship with their adult children carers. This is a high enough proportion to raise concern about the types of "costs" of family care incurred by care receivers, and to focus future analysis upon the experiences of care-receivers as well as caregivers.

The identity of the carer did not make much impact upon elderly people's positive evaluation of care provision and their relationships with their carers. Of the 16 respondents who nominated a daughter as their main family carer, more than half (56%) said that their relationships with their daughter had actually improved as a result of the care they received. Of the 10 respondents who nominated sons as their main family carers, exactly half also pointed towards an improvement in the relationship. By way of important corollary, **whereas 12 per cent of**

participants with daughter carers noted a deterioration in the caring relationship, a greater 20 per cent of respondents with carer sons noted a similarly deleterious consequence.

Of course, the numbers involved were again few. Even so, they indicated that elderly participants were aware of more difficulties in their caring relationships when their carers were sons than when their carers were daughters. Possible explanations here include the proposition that elderly participants preferred daughters to sons as carers and/or that sons failed to provide the rights sorts and amounts of care. Accordingly, the analysis also needs to incorporate an examination of elderly participants' beliefs and attitudes regarding normative filial obligations and their (differential) implications for adult sons and daughters. This is done in the section below. The most notable results here however were that the great majority of elderly respondents pointed towards high levels of affect between themselves and their adult children. Furthermore, the impact of care receipt upon these levels of affect was, in the main, positive although it is important not to overlook the evidence which also emphasised the detrimental effects of the "caring relationship" between elderly parents and their adult children.

4. The Significance of Normative Filial Obligations for Family Care

Seminal work on the conceptualisation of caring by Hilary Graham argues that although "care" from others is a basic human need, it is nevertheless an activity generally perceived and enacted within the context of specific social relationships (Graham, 1983). The family provides the foremost setting for care, and within the family, certain members have a greater socially sanctioned responsibility to care for kin than others. These members are, of course, the female ones: it is no surprise and no accident that mothers, wives and daughters are the major sources of care in society. Caring is intrinsically bound up with the personal and social identity of women: it is what women do and feel (see Dalley, 1988). Explanation of the feminine specificity of care is found within the disciplines of social psychology (e.g., Miller, 1976; Chodorow, 1978), and social policy (e.g., Graham,

1983). A conclusion common to both literatures is that gender differentiated normative obligations within the family are of key significance for the explanation of family care arrangements (e.g., Finch, 1989; Ungerson, 1987; Abel, 1990).

Feminist caregiving literature provides a detailed backdrop to the normative obligations which underpin family care. Its analysis of the effects of gender differentiated socialisation upon the provision of family care highlights not only the feminine specificity of family care but also the role of normative filial obligations in the determination of such care arrangements. In particular, the work of Janet Finch and Jennifer Mason via the Family Obligations Survey provides a wealth of detail about the existence of a public consensus regarding obligations between adult kin and filial obligations to aged parents. Their data suggests that although children are considered duty bound to help frail aged parents, the nature and limits of that support are less well defined (Finch and Mason, 1993, p99). They refute the notion that the eldest child in a family bears the largest responsibility for a frail elderly parent (ibid., p102), but confirm a gender bias towards daughters in terms of practical support and sons for financial support (ibid., p103).

Slightly different, research in the US assesses care-receiver characteristics in the light of perceived filial obligations. Seelbach and his colleagues conducted a series of studies on the filial responsibility expectations of aged parents (Seelbach, 1978; 1984). They examined the extent to which aged parents expected their children to assist them in times of need, and uncovered significant gender differences. Elderly women were more likely then elderly men to endorse living with adult children should they ever become unable to look after themselves. Furthermore, parental expectations in terms of filial responsibility were inversely related to their general morale, suggesting either that parents and children had very different views on filial responsibility, or that children failed to live up to their parents' expectations (Seelbach, 1984).

Perhaps better known, Elaine Brody and colleagues undertook research which investigated the parameters and rules of filial responsibility from the perspective of three generations of women (Brody et al., 1983; Brody, Johnsen and Fulcomer, 1984). Brody was especially interested to examine the impact of women's changing socio-economic status upon preferences for parental caregiving by children. Each generation believed that children should help their parents when needed, and each generation believed that sons as well as daughters should help their parents. Whilst the eldest generation was most in favour of using formal services, each generation stated that a child's employment should not be disrupted because of a parent's need for care.

The Study Data

The Nature of Filial Obligations to the Care of Aged Parents

This section of the analysis addresses elderly participants' attitudes to the family care of elderly relatives. The twelve items which comprise the normative and consensual solidarity scale have been adapted from research developed by Elaine Brody and her colleagues (1983). They examine: the nature of filial obligations towards elderly parents; the significance of gender in those obligations; reactions to receiving care; and reactions to ageing. For ease of reference, they are listed below. The phrases in parentheses match those used in the Tables.

The Nature of Filial Obligations:

1. Friends and neighbours can't be expected to help older people they way their children do. *(Friends and Neighbours)*
2. Nowadays, adult children do not take as much care of their elderly parents as they did in the past. *(Less Help Nowadays)*
3. Parents who have helped their children financially deserve more help from the than parents who have not. *(Money buys more help)*

Differences Between Sons and Daughters

4. When most people need assistance, they are as satisfied receiving it from sons as they are from daughters. (*Same satisfaction*)

5. Sons make valuable dependable helpers when it comes to doing things for their elderly parents. (*Sons dependable helpers*)

6. Adult sons should be expected to do the same kinds of housework as adult daughters for their elderly parents. (*Sons same housework*)

7. Taking care of elderly parents is as much a son's responsibility as a daughter's. (*Sons same responsibility*)

Reactions to Receiving Care

8. One of the good things about having your family help you is you get the chance to help them back. (*Help is Reciprocal*)

9. I don't like to get help from other people unless I can help them too. (*Don't Like Help Without Reciprocity)*

10. Most older people wish they didn't need as much help as they do. (*Wish no needed help*)

Attitudes Towards Ageing

11. Most older people dislike the behaviour of the younger generation. (*Dislike Behaviour Younger Generation*)

12. People grow wiser with the coming of old age. (*Grow wiser*)

Elderly participants were asked to indicate whether they agreed or disagreed with each statement in turn. When participants had difficulty in making up their minds, a "don't know" response was recorded. It should be noted that the three elderly people interviewed by proxy were excluded from the analysis here; they were too confused to proffer personal opinions and it was inappropriate to ask their carers to reply on their behalf because of the attitudinal, as opposed to factual, nature of the data being sought. The tables below accordingly refer to a total sample size of 54.

Table 5.7 reveals that while the elderly participants attributed a clear primacy to their children over the support that friends and neighbours may also provide, female respondents were particularly emphatic on this point. This suggests that

women, (and it is important to remember that the great majority here are widowed), are more reliant upon their families than men. This conclusion supports previous evidence regarding the importance of female contact in the determination of "kin keeping" in intergenerational relations (Finch and Mason, 1993 p97).

Table 5.7 also highlights that despite this widespread primacy respondents accorded to filial care, they nevertheless believed that the amount of help adult children provide elderly parents is in decline. **Seventy per cent of respondents agreed with the statement regarding a contemporary abrogation of filial care, (item 2).** Again the gender difference here is interesting: 77 per cent of elderly men agreed with the filial abrogation thesis in comparison with 68 per cent of women. Thus while the women respondents attached a greater significance to family help than the men, fewer of them considered that children failed to live up to this expectation. This suggests that their level of satisfaction with the amount of help they receive from their children was slightly higher than men's.

The "social hypothesis" of filial abrogation of duty to elderly parents of course denies reality: demographic ageing and increased longevity mean that more children provide care at higher levels than ever before (OPCS, 1992). Of particular interest therefore is that a number of respondents qualified their response to the question about adult children not taking as much care of elderly kin as in the past: **it was not their own family which helped less, but others people's:**

> Yes, because in the past there wasn't these homes and that. But I know I'm a lucky man; my family are around me and do for me very well.
> Respondent 141

> When you get old, some of them *(adult children)* have no time for the old folk. I've a neighbour here and her children couldn't care less. She'll come here for a coffee and a blather and say: "Of all the times I've had coffee here, I've never once had coffee with my daughter." It's bad. But they'll get their day; bound to get their day. No, nowadays young people have no time for the old folk. But I've a good family, and I'm no just blowing about it hen. I've really a good family.
> Respondent 144

Table 5.7: Elderly Participants' Attitudes Toward Filial Care

Statement	AGREE Total n=54 (%)	Men n=17	Women n=37
Filial Obligations: 1. Friends and neighbours	44 (82)	11 (65)	33 (89)
2. Less help nowadays	38 (70)	13 (77)	25 (68)
3. Money buys more help	10 (19)	3 (18)	7 (19)
Sons vs. Daughters: 4. Same satisfaction	33 (61)	11 (65)	22 (59)
5. Sons dependable helpers	30 (56)	11 (65)	19 (51)
6. Sons same housework	30 (56)	9 (53)	21 (57)
7. Sons same responsibility	44 (82)	15 (88)	29 (78)
Reactions to Receiving Care: 8. Help is reciprocal	37 (69)	12 (71)	25 (68)
9. Don't like help without reciprocity	47 (87)	15 (88)	32 (87)
10. Wish no needed help	51 (94)	15 (88)	36 (97)
Attitudes to Ageing: 11. Dislike behaviour younger generation	37 (68)	9 (53)	28 (76)
12. Grow wiser	37 (68)	12 (71)	25 (68)

Table 5.7 also demonstrates that respondents **(70%) believed that financial affairs have nothing to do with the foundations of care between adult children and their aged parents.** In terms of distinguishing between sons and daughters for different care tasks and responsibilities, table 5.7 exhibits a number of results worthy of discussion. While the overall majority of respondents **(82%) considered**

sons to have the same level of care obligation to their aged parents as daughters, there was a notable difference between male and female elderly respondents. Eighty eight per cent of the male care-receivers considered their sons to have the same level of obligation as daughters, in comparison with 78 per cent of women. This suggests that the female participants were more likely than the men to prefer daughters as carers to sons. In addition to these clear-cut findings, participants were far more equivocal about: the types of care sons could be expected to undertake; the dependability of the care provided by sons; and the quality of care sons delivered. For instance, only a slim majority of respondents (56%) stated that sons should be expected to do the same sorts of housework as daughters in caring for their parents. Thus **although participants expected the same level of interest in their care needs from their sons as from their daughters, the way in which that interest was translated into care provision remained stereotyped according to gender.**

Finally, table 5.7 highlights that **elderly participants were uncomfortable with their care dependent status (94%), and placed great import upon being able to reciprocate in some way with their family carers (87%).** Indeed, 69% of respondents stated that they did reciprocate the help they received from their families. Again it should be noted that women were the most antagonistic to receiving care: 97% wished they didn't need help in comparison with 88% of men.

Of primary interest is whether normative expectations regarding filial care differ according to the gender of the family carer. Table 5.8 below looks at this issue. It should be noted that one case is missing in both the son and daughter columns; this again reflects the decision not to obtain attitudinal data in proxy interviews. The results highlight the persistence of the myth regarding filial abrogation of responsibility. Even when elderly participants nominated sons or daughters as their familial mainstays, the majority continued to support the idea that children nowadays provide less help than they did in the past. Of course, this may reflect the fact that sons and daughters performed relatively few of the measured ADL and IADL tasks for their parent. Indeed, when elderly people did not receive help

from any family member, the support for the filial abrogation hypothesis was further intensified.

Results regarding the respective obligations and duties of sons and daughters (items 4 to 7 in table 5.8) revealed that eight out of nine elderly men with a son as their main family carers agreed with the statement that elderly parents are as satisfied with the help sons provide as they are with the help daughters provide. This compares with a minority (47%) of women with daughters as main family carers. These results suggest that participants were satisfied with the filial care they received, albeit from sons or from daughters. When the elderly respondents were without any family help whatsoever though, they were far less likely to agree that sons make valuable dependable helpers (item 5).

One final observation about table 5.8 is that elderly respondents without any family care felt more strongly than those with filial care that family help was reciprocal. Thus it would seem that the anticipated benefits of family care in terms of reciprocity of support are more difficult to achieve once family care is actually being delivered.

Table 5.8: Elderly Participants' Attitudes Toward Filial Responsibility Differentiated by Carer Identity

Statement	**Son** is Carer	**Daughter** is Carer	**No Family Carer**
Filial Obligations:	n=9	n=15	n=22 (%)
1. Friends and neighbours	8	14	15 (68)
2. Less help nowadays	6	8	19 (86)
3. Money buys more help	1	6	3 (14)
Sons vs. Daughters: 4. Same satisfaction	8	7	12 (55)
5. Sons dependable helpers	7	8	19 (86)
6. Sons same housework	6	9	12 (55)
7. Sons same responsibility	8	12	19 (86)
Reactions to Receiving Care: 8. Help is reciprocal	5	9	17 (77)
9. Don't like help without reciprocity	8	12	20 (91)
10. Wish no needed help	9	15	19 (86)
Attitudes to Ageing: 11. Dislike behaviour younger generation	7	12	15 (68)
12. Grow wiser	6	6	18 (82)

Summary and Conclusions

Briefly stated, the prevailing wisdom in caregiving research is twofold and centres around the occurrence of inequality in the provision of support. First, it is recognised that care for elderly people is unequally shared between the formal and informal systems of care: the family is far more important than the state and its various agencies in maintaining functionally impaired people in the community. Second, it is apparent that within the family the provision of care is also unequally divided between different members, with "family care" being a euphemism for care provided by women in their positions as wives and daughters.

Of course, it is critical under current social care scenarios to identify and understand the factors that are related to the provision of family care to frail elderly people. Existing family caregiving research conveys little knowledge of what it means to receive care as an elderly person. Accordingly, this chapter has extended an emerging orthodoxy of care research which states that the family care of elderly people is shaped by the *mutual* expectations of one generation upon the other, the desire and ability of each to uphold such expectations and the emotions that exist between them. Such orthodoxy stresses the structural, affectual and attitudinal characteristics and values which form the foundations and motives of family care.

Specifically, this chapter examined four sets of constructs thought to influence the organisation of care adult children provide frail aged parents: family structure; parent-child contact; the quality of the parent-child relationship; and opinions concerning the normative obligations of adult children to care for their elderly kin.

Key results included the findings that: the large majority of elderly participants (88%) had adult children the slim majority (55%) of whom were daughters and that just under half these children (45%) lived within half an hour's journey of their parents' home although 47% lived an hour or more from their parents.

Overall, here was no significant difference between the elderly participants' sons and daughters in terms of either age or propinquity to their elderly parents.

Investigation of other structural factors known to affect the provision of filial care included marital status, the ages of any children and employment status. The great majority (83%) of elderly participants' children were married and over three quarters had children of their own. Only a fifth had "dependent" children (i.e., aged 16 or under). The slim majority of the elderly participants' were in employment (55%). A higher proportion of daughters than sons were married with children, while a higher proportion of sons than daughters were in employment.

Most important here, where elderly participants had nominated a son as their main family carer , the total number of sons in the families exceeded that of daughters by a factor of more than three. Where the nominated main family carer was a daughter however, they also outnumbered sons but by a factor of less than two. In other words, sons were the main filial carers for their elderly parents in families in which there were fewer daughters, both absolutely and relatively. Furthermore, 44% of all the children of elderly people whose main carer was a son lived within half an hour in comparison to 61% of children of the elderly parents whose main carers were daughters. In other words, when daughters were nominated as their parents' main family carers, they had more proximate siblings than son carers. These results supported the hypothesis that sons become carers in the absence of other available children, especially daughters.

The adverse effect of geographical distance upon the provision of family care was clearly reinforced by the finding that of the 22 elderly participants who received no family help whatsoever, 77 per cent had children but three quarters of these children lived an hour or more away from their parents. .

With regard to levels of contact between elderly participants and their adult children, only 16 per cent of children saw their parents either daily or a few times

a week. These low levels of face to face contact contrasted with high levels of telephone contact between elderly participants and their children, and thus the hypothesis that adult children "abandoned" their aged parents or accorded no importance to their relationship with them was, yet again, rejected. Furthermore, standardising for propinquity, the analysis uncovered no notable differences between the levels of contact between sons as opposed to daughters and their elderly parents.

The elderly participants generally attributed high levels of affect to their relationships with their children although a small minority of children were reported as not making their parent feel loved or cared for at all and almost a quarter were reported as hardly ever, or never, having listened when their parents needed someone to talk to about their problems or worries. These results served to highlight the inherent truth that the emotional bonds which help render family care preferable and superior to formal care are far from infallible. Indeed, just under a third of elderly participants who received assistance from their children stated that their receipt of filial care had been accompanied by a deterioration in the relationship with those carers. This result raises an important question about the "costs" of care receipt and to reaffirm the importance of analysis which concentrates upon the experiences of care-receivers as opposed to carers.

Finally, this chapter explored elderly participants' attitudes towards filial obligations. While elderly participants in general attributed a clear primacy to their children over any support that friends and neighbours may also provide, women respondents were particularly emphatic on this point. This finding supports previous evidence regarding the importance of female contact in intergenerational relations.

Despite this widespread agreement however, the majority of elderly participants supported the statement about the contemporary abrogation of filial care to elderly parents. In particular, while women elderly participants attached a greater significance to family help than the men, fewer of them considered that children

failed to live up to this expectation thereby suggesting that their level of satisfaction with the amount of help they received from their children was slightly higher than men's. Another interesting result was that although elderly participants expected the same level of interest in their care needs from their sons as from their daughters, they nevertheless stereotyped according to gender the sorts of assistance they would expect from their children. Finally, and very importantly, elderly participants revealed a clear and almost unanimous discomfort with accepting any care from their children and stressed the importance they accorded to a "reciprocation" in their relationships with their care providing children.

6

THE ISSUE OF SECONDARY FAMILY CARERS

Introduction

Caregiving studies typically focus upon the motivations and experiences of a "primary carer" (e.g. EOC, 1980, 1982; Nissel and Bonnerjea, 1982; Ungerson, 1987; Qureshi and Walker, 1989). This approach is founded upon observations that care is rarely shared within a family, (Nissel and Bonnerjea, 1982; Glendinning, 1983; Parker, 1985), and that one person, generally a wife or daughter, assumes major responsibility for the provision of care to an elderly relative, (Land, 1978; Brody, 1981; Henwood and Wicks, 1984; Qureshi and Walker, 1989). A radical departure from this position questions the reality of such unshared care. Do other siblings so completely abrogate their filial duty and responsibilities to a single sister or brother? Or is it that research designs which are based upon the self-classification of primary carer status and which include only the "primary" carer as informant create a scenario in which egocentric and socially acceptable responses ignore, or at least under-represent, the caring contribution of other family members? At the very least therefore, there are persuasive arguments why the primary carer lens in family care research should be widened to include other family members.

This chapter suggests that the orthodoxy surrounding "unshared care" requires conceptual challenge and empirical enquiry. The chapter provides a rationale for the inclusion of secondary carers in family caregiving research and proceeds to an examination of elderly participants' and their filial carers' descriptions of the ways in which responsibility for family care is organised and "shared" in practice.

The Significance of Secondary Family Carers

A fourfold rationale underpins the argument that secondary family carers deserve more attention from family care researchers. First, and perhaps most obviously, caregiving research which focuses upon a "primary carer" often overlooks the fact that all adult children are at least implicated in parent care. Even if care is rarely shared within the family, caregiving "stress" research reveals that the support a primary carer receives from his/her own family is vital for their continued caregiving. Without it, carers' stress levels are higher than would otherwise be the case, and their ability to continue caring is placed in jeopardy (Zarit et al., 1980; Braithwaite, 1990). Research which examines the support that carers receive from their siblings, however, (individuals with whom they were brought up and who have a shared history of relationship with their elderly parent), is conspicuous by its absence (Matthews, 1987). This represents a glaring omission in the "care for the carer" agenda; an agenda which tends to concentrate upon the formal support services needed by primary carers and ignores the support that other family members may provide.

Sibling relationships are unique in that they have a high degree of permanency and represent the only intragenerational links to be characterised by common background and experiences. Although there is some evidence to suggest that differential treatment of siblings by parents has a role to play in explaining why one child in a family can be so different from another, (e.g., Brody et al., 1992), siblings nevertheless share the same parents and same socio-environmental upbringing. Thus it is possible that a sibling's motives to provide care to an elderly parent are the same: duty, affection, reciprocity and instrumental rewards, (Bulmer, 1987). With regard to caring for frail elderly kin however, we do not know how brothers and sisters interact either with each other or with their elderly parents in the organisation and provision of family care.

At issue here is whether the siblings of so-called "primary carers" completely abrogate their filial duty to frail elderly parents and if they do, how they manage it

when the ill-effects of informal care provision are so apparent ? Do siblings discuss the distribution of care provided by themselves and others for their frail elderly parents? Is there evidence of any negotiation between siblings in terms of the levels and scope of support required by frail elderly parents? How fair is the organisation of filial care perceived to be? These questions are not amenable to analysis in studies which focus upon the experiences and opinions of a lone, necessarily self-defined, "primary" carer. In particular, research needs to address the reality of unshared care. Research designs which include only a self-defined "primary carer" as informant may encourage responses which systematically ignore or under-report the contribution of other family members. In other words, carers' descriptions and explanations of the care they provide may be prone to egocentric bias.

The second aspect of the rationale derives from a sociological explanation of intergenerational relations. In his study of the families of elderly people in east London almost thirty years ago, Peter Townsend argued that the structural features of a family (especially its size, gender profile and geographical proximity), directly affected the types of relationships that took place between family members (Townsend, 1968). As the previous chapter demonstrated, this makes intuitive sense: the structure of a family describes and contains the total amount of potential kinship resources available to a frail elderly parent (Bengtson et al., 1985, p318). Moreover, the sociological and economic developments discussed at the beginning of chapter four in the form of changing family forms, increased geographical mobility and the importance of women's employment to family incomes, suggest that non-traditional carers within the family may increasingly be called upon to assume (some) responsibility for caregiving functions previously relegated to female family members (Abel, 1987). Thus knowledge about traditional non-carers' resistance to providing care for their elderly kin is valuable in developing public policies designed to encourage and support family carers (Ungerson, 1987). The process and circumstances of either refusal or inability to assume responsibility for the care of an elderly parent are thus important issues

which require analysis. This can only be done via reference to all of the adult children contained in a family.

Third, studies of kinship obligation between adult children and their aged parents suggest that it is not societal norms which are gender-specific, but their application. Again, this issue was explored in the previous chapter and the results revealed therein emphasised the accuracy of this proposition, (refer to table 5.8). More specifically, kinship obligations are thought to be permissive rather than binding; abstract rather than defined; and ambiguous rather than systematic (Firth et al., 1970). Janet Finch therefore argues that although filial obligations to elderly kin comprise normative and affective components, they merely determine the "ground-rules" of those obligations (Finch, 1987). Finch and Mason identify "procedural rules" in the determination of filial obligations to elderly kin, and these are characterised by joint decision-making, practicality, fairness and quality of prior relationships with the elderly care-receiver (Finch and Mason, 1990, p169-72). Although research in this area remains in its infancy, such conclusions suggest that the ways in which families put into practice their views on kinship obligations to elderly kin depends upon the input of more than one person: it involves the family unit as a whole.

Fourth and finally, there is the matter of chronology. Intergenerational solidarity is a key concern in the caregiving literature (Allan, 1988; Dant, 1988; Daatland, 1990). Despite popular currency, social gerontologists have long since dispelled the "myth" of the family abandonment of elderly members (Townsend, 1957; Shanas and Streib, 1965; Shanas et. al., 1968; Shanas, 1979; Brody, 1981 and 1985). More recently, however, research illustrates that the provision of supports to elderly kin precedes, but intensifies with, the development of functional impairment (e.g., Walker and Pratt, 1992). Thus there exists the notion that caregiving to elderly kin represents the "intensification of a pre-existing pattern of aid-giving that is evident in female intergenerational relationships" (ibid., p3). Such a conclusion reinforces the necessity of disaggregating the "caring process". Specifically, the analytical lens used to focus upon family care requires widening.

Most significantly, the "wide-angled" perspective needs to include all those care-related activities undertaken by family members who are effectively treated as non-carers because the method of analysis examines only the circumstances and characteristics of "primary" carers.

Existing Evidence on "Shared Care"

Conceptually therefore, distinctions need to be made between primary carers and any other relatives involved in the care of frail elderly people. Arber and Ginn assert that as regards looking after elderly relatives, families contain both carers and helpers, and explain the differential input of the two groups in terms of: timeliness; indispensability; responsibility and organisation; emotional care; and severity and nature of dependency (Arber and Ginn, 1990, p439). Understanding why and how certain family members are able to avoid caregiving responsibilities for a frail elderly relative furthers understanding of the familial division of labour, as well as the operation of distributive justice within the family. Moreover, if certain family members are either "selected" or "self-selected", (Ungerson, 1987), as primary carers simply because they have less power than other family members to refuse such selection, this may have ramifications for the quality of care they can procure (ibid., p144).

While the British literature pays relatively scant attention to the matter of secondary family carers, the parallel North American literature shows greater interest. Elaine Brody and her colleagues have compared the caring activities of primary carer daughters with their local brothers and sisters in a very direct fashion. Specifically, these researchers addressed the amount of help given to elderly mothers, the effects of caregiving and the problems and benefits of interactions with siblings concerning the care provided (Brody et al., 1989). Collectively, brothers provided the least help and were least negatively affected by parent care: they experienced the least strain and were the least troubled by sibling interactions. Brothers also derived more "uplift" from interactions with their siblings than did primary caregivers, (i.e., daughters), though less than the sister

group. The sister group fell in the middle ground on most measurements of caregiving effects: they provided less help with less negative effect and strain than their primary caregiving sisters, but significantly more than their brothers. Interestingly, however, the sister group experienced more guilt than either the primary caregiving sisters or brothers groups, and thus expressed more discomfort than brothers about being a secondary, as opposed to primary, carer.
Brody and colleagues also addressed the quality of sibling relationships and described the prevalence of conflicts relating to parental care between primary carers and their siblings. Sixty per cent of primary carers complained that their siblings failed to help as much as they should with their elderly parent. Siblings on the other hand complained that the primary carer failed to recognise or appreciate the help they gave (Brody 1990). There is a real dispute here that only empirical research which addresses the family unit as a whole can settle. In the meantime Brody concluded that:

> little information exists about the interactions of the siblings, what siblings other than the primary caregiver actually do, the strains they may experience, or their perspectives on the situation.
> Brody, 1990, p16.

A study which focused more precisely on the issue of egocentric bias in carers' estimations of the help provided by their siblings has been conducted by Canadian psychologists. They confirmed that filial carers "reliably" overestimated the amount of care they provided their parents and that this overestimation increased with the level of care provided (Lerner et al., 1991, p754). Carers emphasised the unfairness of caregiving arrangements, and pointed to the need for siblings to increase their contribution in order to improve the situation. Significantly however, carers expected their siblings to disagree with their estimation of the division and fairness of care between them (ibid). Lerner and his colleagues provided two explanations for the egocentric bias in the carers' assessments of sibling support. First was a discrepancy between knowledge concerning personal caregiving costs and estimations of costs incurred by siblings. Second, carers were "motivated" (ibid., p753) to reduce personal caregiving costs whilst simultaneously

ensuring that the care needs of the aged parent were met, thereby providing the carer with an incentive to underestimate the contribution made by their siblings.

Also in Canada, and based upon Peter Townsend's (1968) research which demonstrates the importance of female kinship networks in intergenerational relations, Sarah Matthews (1987) examined how siblings share in the care needs of an elderly parent. In a study of 50 pairs of employed and non-employed sisters (each of which had at least one "non-institutionalised" parent), Matthews found that sisters had very clear expectations of each other's responsibilities for parent care, especially when there were no other children. Matthews also found that the number and gender of adult children affected how equally responsibility for the care of an elderly parent was divided. Families comprising two adult daughters only were the most likely to report sharing equally in providing care to elderly parents; as opposed to families of four or more siblings in which the organisation of care was described as "mixed, not all help" (ibid., p57). Furthermore, the respondents indicated that their brothers adopted a less significant role in the provision of care than themselves. Most important though, Matthews found that the sisters had very different perceptions of how responsibility for an aged parent was actually divided between themselves and any other siblings, of how close their families were, and of how adequately their parents' care needs were being met (ibid., p58).

In further research, Matthews and Rosner identified four patterns of the division of care provided for elderly parents by adult children: no adult child helping; all children helping equally; all children helping but unevenly divided; and not all children helping. The latter two patterns were associated with larger family size and the presence of sons. Significantly, they also found that sibling conflicts concerning the division of care became so profound that siblings withdrew their help or support (Matthews and Rosner, 1988).

Strawbridge and Wallhagen (1991) examined family conflict over caregiving activities for elderly parents and found that 40 per cent of their respondents

experienced "relatively serious conflict with another family member" (p775). These conflicts adversely affected primary carers' perceptions of burden and assessment of their mental health and had a deleterious effect upon the quality of relationships with their aged parents (ibid). Interestingly, brothers and sisters were equal in being the source of conflict: primary caregiving sisters expected as much help from their brothers as they did from their sisters, and were just as upset when their brothers failed to meet their expectations as they were with their sisters.

By way of conclusion at this point, it must be admitted that these findings in themselves are perhaps not terribly surprising. For instance, in terms of any egocentric bias in primary carers' calculations of sibling support of elderly parents, perhaps it is inevitable that different people understand different things from complex social interactions and negotiations. Nevertheless, the results revealed above are enough to at least plant the question as to the accuracy and validity of research designs which depend upon the descriptions and explanations of a lone informant, especially when societal norms may encourage the provision of "socially acceptable" answers to questions which probe into issues such as filial piety and public demonstration of "love" for one's parent. Furthermore, because caregiving for an elderly parent is a time consuming, physically arduous and emotionally draining undertaking augmented over time as dependency levels increase, primary carers may change the significance they attach to (pre)existing or established patterns of interaction between their sibling(s) and the care receiving parent. For example, the brother who visits occasionally and whose visits are eagerly awaited and enjoyed by the parent may become a source of irritation and resentment for the daughter whose daily vigilance and care go unremarked, unrecognised and unrewarded by that same parent.

The assertion here therefore is that the provision of care to an elderly parent is very much a family affair. The experience of providing care inevitably affects the balance and quality of relationships within the family: a conclusion Elaine Brody first pointed out in her well known memorial lecture and paper about family care as normative stress:

> Emotional support from spouses (Sussman 1976), siblings (Cantor 1983; Horowitz 1985), and other relatives, (Zarit, Reeves, and Bach-Peterson 1980), mitigates the caregivers' strains. But when changes in the family homeostasis stimulate interpersonal conflicts, relationships are affected negatively between husbands and wives, among adult siblings, and across generations.
> Brody 1985 p22.

The design of studies which attempt to capture the dynamics of family caregiving need to address more than the self defined "primary" carer. To date however, research which concentrates upon the caregiving relationship is limited to the vertical links that exist between a single, necessarily self-defined, "primary", carer and care recipient. Furthermore, analyses of such links tend to involve a one-way analysis in which elderly people's experiences of care receipt remain a topic for further examination. The horizontal links that exist between a primary carer and his/her siblings are almost totally overlooked. Of course it is undeniable that some siblings are more involved in caring for an aged parent than others, but the reasons why this is the case, the patterns of interaction between adult children, and the ways in which sibling relationships impede or enhance the effectiveness of family caregiving also need to be fully explored.

The Study Data: Identifying Secondary Family Helpers and Defining the Scope of their Support

a: The Perspectives of Elderly Care Receivers

In order to identify any occurrence of "shared care" within the family, elderly care receivers were asked a number of questions. First they were asked to identify their carers for 13 specific tasks (see previous chapter). With the totality of practical support in mind, they were then asked to nominate their main family carer. Such a sequence of questions means that the respondents were focused very much upon practical support. Finally, the elderly respondents were asked to identify the family member they "next most rely upon after" their main family helper. This phrasing deliberately avoided use of the term "primary carer": as is clear from the

discussion above, knowledge concerning the functions and activities of secondary carers is cursory and so the primary intention was to encourage elderly care receivers to indicate whether or not any other family member was implicated in their care.

The elderly participants' responses are illustrated in table 6.1. **Over one third (36%) of all respondents revealed that they had more than one family carer**. Furthermore, when the 22 respondents who indicated that they received no family care whatsoever were excluded from the analysis, this percentage increased to more than half of the relevant respondents (57%). In other words, **of those elderly people who described themselves as being in receipt of any family care, over half identified a second family** member they relied upon for their care needs to be satisfied.

This is a significant result. It contradicts the orthodoxy that care is rarely shared within the family and suggests that from the elderly participants' perspective, the provision of family care was not experienced in terms of a single carer-care receiver dyad. When any family care was received, a relatively high proportion of care receivers identified at least two simultaneously operative family caregiving relationships. Of course, this is not to suggest that these different family caregiving relationships were either equal in scope or magnitude of assistance provided. Indeed, tables 6.3, 6.4 and 6.5 below reveal that there are very apparent "primary" carers for individual caregiving tasks. Rather, the conclusion is that **when elderly participants received any family care at all, they more often than not admitted to a reliance upon more than one family carer.** Their elderly participants' experiences of receiving care would thus appear to be more complex than examination of the activities of solitary carers might allow.

Table 6.1: Elderly Participants' Identification of Primary and Secondary Family Carers

N=57 (5)	MAIN CARER	SECOND CARER
Daughter	16 (28)	10 (18)
Son	10 (18)	9 (16)
Spouse	7 (12)	1
Other	2	-
NO FAMILY CARER	22 (39)	37 (64)

With regard to the identity of the "secondary carers", table 6.1 illustrates that there was very little numerical difference between sons and daughters: **18 per cent of elderly participants identified a daughter as their second carer,** (29% of respondents excluding the 22 with no family carer whatsoever), **whilst 16 per cent identified a son** (26%). A note of caution is required in the interpretation of these results: only 20 secondary carers were identified in total. Caveat aside, these results reveal that whereas there were more daughters than sons nominated as "main family helpers", the identity of secondary family carers was less gender-specific.

Table 6.2 below examines the variety of "shared care dyads" that existed; the combinations of different family carers that elderly respondents described as their familial mainstays. The significant feature of table 6.2 is that **family care was most commonly "shared" when daughters were the primary carers**. For instance, only one spousal carer received any help from another family member (thereby reaffirming the solitary nature of spousal care provision), in comparison to half of the sons and over four fifths the daughters nominated as main family carers. Indeed, **only 12 per cent of daughters identified as main family carers were also identified as sole family carers**. Of course, the numbers involved are small and the elderly people interviewed are not necessarily representative of the elderly population. Nevertheless, these results provide stark contradiction to the

orthodoxy concerning women's solitary and unsupported status as filial carers: second carers were more evident in families in which daughters had been nominated as main carers than they were when sons were so nominated. While this result reflects, at least in part, the previous conclusion that sons become carers in the absence of other siblings, especially sisters (see previous chapter), the results here illustrate that when adult daughters cared for their elderly parent(s), the majority of them were supported in some way by other family members.

Table 6.2: Pairs of Family Carers

Second Carer		Main Carer	N=35	
n = 20	Daughter n=16 (%)	Son n=10	Spouse n=7	Other n=2
Daughter: n =10	8 (50)	2	-	-
Son: n = 9	5 (31)	3	1	-
Spouse: n=1	1	-	-	-
NO SECOND CARER	2	5	6	2

In other words, elderly care receivers suggested that their adult daughters did not care alone; other family members helped:

> I get tremendous help from my family because, you know, they do everything I can't tell between them (*two daughters*). They do everything they can. They collect my pension and manage my finances and everything. If it was too much for them they would tell me. But they both do everything they can.
> Respondent 101

> They're (*respondent has 5 children*) all so good and helpful. They've all got cars and can get here. Mind you, my daughter wants to take over all the time, but they all do what they can.
> Respondent 142

This is not deny, however, that there might have been inequalities in the levels and types of support between the different carers: indeed the quotes above indicate that this was highly likely. Nevertheless, the results presented so far provide

confirmation that the orthodoxy surrounding "unshared care" requires reinterpretation.

The most common shared-care dyad revealed in table 6.2 was the daughter-daughter combination. This is not surprising given the large volume of previous research which stresses the feminine specificity of family caregiving (see Aronson, 1990).

Different configurations encourage questions about the content and amount of care provided by primary and secondary carers. For this reason, the nine ADL and IADL tasks for which family care was most common (as stated in chapter four) were examined in order to reveal the scope of support provided by secondary family carers. Table 6.3 examines the scope of secondary family support when a daughter was nominated as the main family carer by the elderly care receiver. Table 6.4 conveys the same information when a son was the nominated main family carer, while table 6.5 presents equivalent data when spousal care was the nominated primary source of support.

Each table highlights the important point that **the scope of support provided by other family members was very limited.** For instance, table 6.3 reveals that only four sisters, and no brothers, of the 16 main carer daughters provided assistance with light housework, while only three sisters helped with grocery shopping. Although the contribution by siblings was more widespread when sons were the main carers, there is **virtually no evidence of shared care when spousal care was provided.**

Table 6.3: Help Received from Others

When Daughters Are Main Family Carers

CARER IS **DAUGHTER** N=16 (%)		SECOND	CARER		
TASK DONE	Daughter	Son	Other Family	Paid Worker	NO OTHER HELP
Groceries	3	-	1	2	10 (63)
Heavy H/work	2	1	1	-	12 (75)
Pension/Bills	1	-	-	-	15 (94)
Main Meal	1	1	-	2	12 (75)
Heavy Laundry	1	-	-	-	15 (94)
Light Laundry	1	-	-	1	14 (88)
Walk End of Road	-	-	-	1	15 (94)
Bath/Shower	-	-	-	1	15 (94)
Light Housework	4 (25)	-	-	3	9 (56)

Table 6.4: Help Received From Others When Sons Are Main Family Carers

MAIN CARERS= **SONS** (n=10) Task Undertaken	Daughters	SECOND Sons	CARER Other Family	Paid Worker	NO OTHER CARER
Groceries	1	1	-	1	7 (70)
Heavy H/work	2	1	-	-	7 (70)
Pension/Bills	1	1	-	-	8 (80)
Main Meal	1	-	-	1	8 (80)
Heavy Laundry	1	-	-	-	9 (90)
Light Laundry	-	-	-	1	9 (90)
Walk End of Road	2	-	-	-	8 (80)
Bath/Shower	-	-	-	-	10 (100)
Light Housework	-	1	-	1	8 (80)

Table 6.5: Spouses as Primary Carers and Shared Care

MAIN CARER= SPOUSE N=7		SECOND	CARER		
TASK DONE	Daughter	Son	Other Family	Paid Worker	NO OTHER HELP
Groceries	-	-	1	-	6
Heavy H/work	-	-	-	-	7
Pension/Bills	-	-	-	-	7
Main Meal	-	-	-	-	7
Heavy Laundry	-	-	-	1	6
Light Laundry	-	-	-	1	6
Walk End of Road	-	-	-	-	7
Bath/Shower	-	-	1	2	4
Light Housework	-	-	1	3	3

An interesting contradiction exists therefore between the results presented in tables 6.1 and 6.2 and tables 6.3, 6.4 and 6.5. When elderly participants were asked simply to identify the family member they relied upon the most and then the family member they next most relied upon, of the 35 who were able to nominate a relative in the first question, 57 per cent also identified a second family carer. Yet when the same 35 elderly participants were asked to pinpoint the scope of the secondary support they received for specific tasks, very few provided examples of carers either sharing responsibility for discrete tasks or dividing out those tasks between them. Indeed, **the scope of the care provided by these second family carers was so limited as to be insignificant except for a few isolated tasks undertaken within a particular set of family relationships.**

This contradiction forces the obvious conclusion that elderly care-receivers' understandings and experiences of family care were far wider than instrumental assistance: the provision of practical support was not the only yardstick by which they measured "family care". By identifying a second family member they relied upon for help yet simultaneously demonstrating the paucity of practical assistance their second carers provided, elderly participants effectively emphasised the non-instrumental aspects of family care; the emotional backdrop to practical care:

> Oh, he worries about us (*son*). He's on that phone. You see, he travels with his work so he cannae very well come. If he gets back on a Wednesday say, he's on that phone the Thursday...always. He always phones us then before he goes away again. He's very good to us, he's a good son, very thoughtful. And he always comes if he can. If he's travelling nearby, he'll always come in. It depends where he's working. When he comes up, if he's a spare week-end, he'll come up with his wee daughter and we sit here till 3 or 4 in the morning. My husband goes on up to bed....that's how we are (*respondent and her son*) when we get together.
> Respondent 145

This observation that elderly people "rely" upon adult children whom they simultaneously describe as providing very little practical support is something that merits further examination in family care research. At the very least it has something to say about our understanding of the "dependency" used to characterise relations between frail elderly people and their caregiving adult children. Such dependency extends beyond the simple exchange of practical supports and emphasises the vital importance frail elderly people accord to the emotional bonds which link them with their adult children.

b: Shared Care from the Perspective of Nominated Primary Carers

To recap briefly from the previous chapter, 18 interviews were conducted with adult children nominated as primary carers by elderly care receivers. Of these, 11 were daughters and 7 were sons. A primary goal for the interviews with primary carers concerned the need to further understanding about the extent to which any care for elderly parents was shared between adult siblings. It is also pertinent to recall, therefore, that although the 18 carers identified a total of 30 siblings, only

29 sisters and brothers were recorded in detail because of coding frame conventions; that is, the coding frame was limited to four siblings and one primary carer had five meaning that her youngest sister was excluded.

The definition of "shared care" applied in the interviews was wide-ranging and examined under a number of different guises. These included: the identification of siblings who participated in parental care; the content of care "shared" between siblings; the reasons why some siblings failed to participate in parental care; an evaluation of the fairness of the organisation of filial care; filial debate about parental care needs; and a consideration of future care organisation for parents.

i: Establishing Probable Limits to Shared Care

By way of necessary preamble to their descriptions of any "shared care" in the family, carers were first asked to describe their siblings in terms of certain practical features known to affect the provision of family care: journey time from elderly parent (Spitze and Logan, 1990); employment and unemployment (Archbold, 1983; Lewis and Meredith, 1988; Qureshi and Walker, 1989 p115); and dependent children (Brody, 1981; Finley, 1989).

"Journey" was defined in terms of the time it took siblings to travel to their parents' homes using their usual form of transport; private car, public transport or foot[1]. This primary interest in travel time is based upon the common sense observation that lengthy journeys constitute an obvious impediment to the provision of care: potential carers who have to undertake lengthy journeys are unable to respond speedily to emergencies or unanticipated care needs; and they are less likely to provide the normal, repetitive and timely activities which describe the daily business of care provision.

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[1] Ethel Shanas (1979b) devised a six fold classification of journey time which I used to code my data: same household; less than 10 minutes away; 11-30 minutes; 31-60 minutes; more than an hour but less than a day; and a day's journey or more.

With this in mind, the 18 carers revealed that **over a quarter of their 29 siblings lived within a half hour journey of their elderly parents.** Other impediments notwithstanding therefore, the assumption can be made that these siblings were at least implicated in the practical support of their frail elderly parents. A further fifth of carers' siblings lived between half an hour and a one hour journey from their elderly parents. The degree to which these siblings were implicated in their parents' support was more precarious: those with a car may have been able to accommodate the care needs of their parents, but those dependent upon public transport would have been constrained by timetables and thus unable to attend to their parents in the very early mornings, late evenings, Sundays and holidays. Finally, **over half the carers' siblings lived an hour or more away from their elderly parents**. The assumption held here was that these siblings were unlikely to be implicated in any daily form of care provision for their elderly parents: indeed, 8 siblings lived a day's journey time or more away[2].

Twenty two of the carers' 29 siblings were in employment: 12 full-time and a further ten part-time. Although the differences between part-time employment and full time employment have been shown to have negligible effect upon women's caregiving (e.g., Brody and Schoonover, 1986), the general impediment that employment creates for caregiving is well acknowledged (i.e., Green, 1988 Table 2.9). Of course, when gender is added to the equation, the interaction between employment and care provision is complicated further. Qureshi and Walker for instance found that unemployed sons had even less contact with elderly parents than did sons in employment (Qureshi and Walker, 1989, p115). In terms of gender therefore, it is important to note that almost identical proportions of brothers and sisters were in employment: **of the carers' total of 16 brothers, 12 were in employment; of the 13 sisters, 10 were in employment**. The proportions differed markedly however in terms of the level of employment: 10 of the 12 employed brothers were in full-time employment in comparison with 2 of the 10 employed sisters.

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[2] Siblings lived as far away as Australia, America and Japan

The ages of the siblings' youngest children were ascertained in order to discover whether or not siblings had dependent children living at home with them who might compete for attention and compromise their ability to provide high and sustained levels of support for their aged parents. Twenty-four of the 29 siblings had children, but **only 4 siblings had a child aged 16 years or younger** suggesting that siblings' family networks did not appear to present much potential conflict between children's needs and elderly parents' needs. It must be admitted though that information on the involvement of the carers' siblings with grandchildren was not obtained during the interviews; this was probably a mistake since a couple of carers talked in terms whereby they placed the needs of frail elderly parents in direct competition with those of young grandchildren.

As regards the potential practical support the carers' siblings were able to offer their elderly parents therefore, **only a quarter lived "on hand"; over three quarters were in employment; but very few had dependent children.** These results suggest that there were probable limits to the practical support the carers' siblings were able to give.

ii: Carers' Identification of Care Shared with Siblings

Before ascertaining their views on the levels and types of any sibling involvement in their elderly parents' care, primary carers were asked to identify the family member they considered their elderly parents "relied upon the most". Of course, this wording was the same as that asked of elderly care receivers; the intention was to identify any discrepancy between the perceptions of elderly participants as care receivers and their nominated "primary carers" regarding the identity of those contributing the major proportions of family care.

Sixteen of the 18 primary carers agreed with their parent's nomination and confirmed that they were the family member their parents relied upon the most. The remaining two carers, both of whom were sons, identified their other

parent as the most important family carer. This means that little confusion existed between carers and care receivers as to the identity of main family carers.

Again, following the format used during the care receiver interviews, primary carers were also asked to identify the family member their elderly parents next most relied upon. The pertinent result here is that **the great majority of primary carers (15), identified a second family carer.** In other words, although these adult children recognised the primacy of their own care contribution, they also realised that their care was not the only family support their elderly parents relied upon. This result again challenges the orthodoxy about "unshared care" and the depiction of filial care for elderly people as a solitary and unsupported undertaking. Rather, carers, just like their care receiving elderly parents, understood family care to be organised around at least three family members.

With regard to the identity of secondary sources of family support for elderly people, **one half of all the primary carers identified a brother or sister.** By way of contrast, over a fifth identified their spouse as the family member their parents next most relied upon. The interesting aspect of this latter result is that **all four carers who nominated their spouses were daughters who nominated their husbands**: not one son indicated that his wife acted as his parent's secondary source of support.

A major focus of interest during the interviews with filial carers concerned their experiences of and reactions to any care provided to elderly participants by any of their siblings. It is important to note therefore that one third (6) of all carers identified a sister as their parents' second most important carer and three carers identified a brother. When the two carers without siblings were excluded from the analysis, **38 per cent identified a sister and 19 per cent identified a brother as their parents' secondary source of family support.** These nine siblings are discussed in greater detail below.

Turning to the variety of patterns of shared-care between siblings, the sister-sister partnership was the most common arrangement. More specifically, of the 11 daughters interviewed: five indicated that a sister was the second most important family carer for their elderly parent; four identified their husbands; one identified a brother; and the final daughter reported that she alone in the family cared for the parent. The participation of the daughters' husbands, the sons-in-law, is a notable result. The effects of marriage upon care provision are usually discussed in terms of their gender specific relevance for women in their role as daughters-in-law. The data here however stress that men's caregiving activities similarly resulted from the ties of marriage.

With regard to the seven sons interviewed, the most common shared-care scenario was that of the brother-brother arrangement. Specifically, two primary carer sons identified a brother as the second most important family carer; one identified a paid home help; one identified another relative; one stated that he is the second most important carer after his other parent; while the final two sons stated that they acted as sole family carers.

Commenting upon the primacy of family care, **only three carers stated that their parents' most important source of help derived from outside the family**. In each of these three cases, the home help was identified as the parents' most important source of support. By way of conclusion at this point, then, the most common form of sibling care was that of sister-sister; a combination which accords with the experiences of elderly care-receivers (see table 6.2 above).

iii: Siblings as Secondary Carers

This third part of the analysis deals only with those 9 siblings, (6 sisters and 3 brothers), identified by primary carers as the family member their elderly parent "next relied upon the most". Very simply, primary carers were asked:

Can you describe what this sister/brother does for your father/mother?

The phrasing of this question was deliberately broad. The intention was to provide carers with the widest remit possible in their descriptions of how siblings participated in the care of their elderly parents. This first notable aspect of carers' replies to this question was that they had a very clear view of the precise nature of their siblings' caring contributions:

> She *(sister)* phones down to see if she's *(aged mother)* OK and she'll put up the curtains and things like that. And she helps in the house as well. If she (*mother*) wants any ironing, she'll do it. She (*sister*) finishes work at 1 o'clock most days and generally goes in for her lunch with Mum. But she can't do a lot of the housework because she has her own family; that's down to me. But she changes her (*mother's*) bed. Really, Mum depends on her to talk to. I'll go round there at lunch times and they're both blathering away. And she (*sister*) does all the paperwork and checks the bills and that.
> Carer 126

> He does any maintenance for the house; especially anything electrical. And maybe twice a month he'll take him out for a meal or over to his place in Edinburgh. Or he'll have him over for a few days. He sees him at least fortnightly.
> Carer 141

More specifically, responses revealed that carers tended to categorise the assistance provided by sibling secondary carers according to three factors: the types of assistance provided; the amount of assistance provided; and how the care siblings provided fitted in with their own caring schedules or agendas. For instance, respondents would mention a specific task such as grocery shopping, how often their sibling did the shopping for their elderly parent and offer some reference as to how this fitted in with their own caring activities:

> My sister does the main shopping, although that's not as much as before. She also gives Mum a bath every week and does her hair. She does any heavy housework that needs doing like the curtains. And then she shares with me doing Mum's dinner. She goes round there about 3 or 4 times a week. You see, I worked until the last two years. But when I stopped, I took over most of the caring from my sister ... but she did it before because she had never worked. But it's more manageable with the two of us sharing things.
> Carer 101

> Just the same as me in a way, I suppose. She goes round a lot, and we both take her to the bingo twice a week. And she's (*sister*) down there every Saturday: she spends all day there because she works during the week like. It's me that's there every day, cooking her dinners and fetching her messages. I sort out all her affairs; but we share it 50-50 really.
> Carer 117

The references primary carers made about how their siblings' efforts affected their own care activities are very interesting and provide an indication that some form of caring partnership, whether articulated or implicit, pre-organised or ad hoc, occurred between primary carers and their siblings. The quotations also drew attention to the fact that primary carers and their siblings sometimes provided the same sorts of caring functions on behalf of their parents and duplicated one another's activities. Not one carer, however, made any reference to such duplication being either wasteful or unnecessary. Of course, some primary carer and sibling pairs undertook different tasks on behalf of their elderly parents: most commonly, primary carers reported that siblings undertook discrete household maintenance/management tasks while they assumed responsibility for day-to-day care tasks. In such cases, the care management style was one of complementarity, albeit unequally divided.

Finally here, the primary carers gave no indication that the caring contributions of siblings were undertaken on a contingency basis. Indeed, the high degree of certainty illustrated by primary carers regarding the nature and extent of their siblings' caring contributions suggests either that the responsibility for care tasks was recognisably, perhaps even formally, divided between primary carers and their siblings, or that the division of tasks resulted from a process of evolution over time.

In order to evaluate whether the dual efforts of primary carers and their siblings were effectively managed, however, carers were asked more direct questions about the contributions siblings made to their parents' care.

iv: The Importance Accorded to Siblings' Assistance in the Care of Elderly Parents

Specifically, carers were asked how helpful their secondary carer siblings were in caring for their elderly parents in terms of five features of family care: practical day to day care; liaison with the SWD and other welfare agencies; arranging necessary appointments on behalf of the elderly parent; providing their parents with emotional support; and providing themselves with emotional support. These features were designed to encapsulate the practical "labour" of family care as well as the emotional foundations of family care. The scale applied was 1 to 10 where 1 equated to "not at all helpful" and 10 equated to "essential"[3].

With regard to the practical help with the day to day care of their elderly parents, **over half of the relevant primary carers (5) scored their siblings' efforts as 3 or below.** These carers thereby revealed that the practical "labour" of care, the "tending" aspect of care in Parker parlance, was unevenly distributed between themselves and their siblings and that siblings offered few practical supports. **At the other end of the scale here, however, two carers accorded a score of 10 to the practical help their siblings provided**. These relevant primary carers were daughters and the siblings they rated so highly were both sisters. For these sister-sister carer couples at least, the practical role of the secondary carers was therefore vital in the eyes of the primary carers.

With regard to liaison with the SWD and other welfare agencies, **over half of the primary carers (5) rated the efforts of their siblings as 1 "not at all helpful"**. Again two carers rated their siblings' efforts as "essential": in this case however the primary carers were a son and daughter while both siblings were sisters. These results need to be read in conjunction with the types of contact primary carers themselves had with the SWD and other agencies. They are discussed in detail in chapter 7, but it is pertinent to note here that primary carers also had low levels of

[3] My pilot interviews with carers revealed that carers were far from ambivalent about the importance of their sibling's caring contribution. I wanted my scale to exaggerate the strength of any feeling and therefore decided to deploy a fairly wide scale of 1 to 10.

contact with formal care agencies. Over a third of carers had never come into contact with anyone from the SWD, including home helps working directly in their parents' homes. Taken together, these results suggest that family carers were not incorporated into any service planning, assessment or review procedures operated by the SWD or other welfare agencies.

Patricia Archbold (1983) divided different family carers into care providers and care managers. The purpose of asking primary carers whether or not their siblings took responsibility for arranging necessary appointments on behalf of their elderly parents was to provide a proxy for such a "management" role. The results reveal that primary carers accorded very low priority to their siblings' efforts here: two thirds of carers (6) scored their siblings as "not at all helpful". At the other end of the evaluative scale however, two carers evaluated their siblings' efforts as "essential"[4] which confirms that the care management function of secondary carers does exist.

The results pertaining to the importance which primary carers attached to the emotional support their siblings provided to themselves and their elderly parents painted a very different picture. **Almost half the carers (4) stated that the emotional support they received from their siblings was "essential".** Of the remaining five carers, 3 accorded their siblings a score between four and six, whilst the other two awarded a score of three. In other words, all of the primary carers accorded some value to the emotional support they received from their secondary carer siblings. This result is resonant of research cited at the beginning of this chapter: primary carers valued the emotional support they received from their siblings for the care they provided elderly parents. It is important to recall that primary carers considered their siblings' practical contribution to the care of elderly parents to be of little importance because **these contrary findings suggest that primary carers and their siblings were not in conflict over the unequal practical support they respectively provided.** In other words, the fact that primary carers did not accord much importance to the practical care their siblings

[4] The carers who consistently rated their siblings efforts as essential were three daughters

provided to the elderly parents does not appear to have marred relationships between them. At some level therefore, primary carers had accommodated the unequal division of labour that existed between themselves and their siblings and were grateful for the emotional support their siblings provided.

Primary carers attached even more importance to the emotional support their siblings provided to their elderly parents: over half the carers scored their siblings' contributions as seven or over. In fact, four carers awarded a score of 10, "essential", while another carer awarded a score of 9. Of the remaining four carers, three awarded their siblings a score of 5 while the other gave a score of 4. In other words, **the emotional support siblings provided to the elderly parents was highly valued by primary carers**. Again, the importance accorded by carers to their siblings' roles related not so much to what they did but rather to the concern they showed.

When these results are read in conjunction with the descriptions provided about siblings' care activities, it becomes clear that while primary carers were very certain about what their siblings did on behalf of their elderly parents, what they valued most was their siblings' involvement in the emotional drama which family care directs. There appeared to be a close and positive relationship between primary carers and those of their siblings who participated in the support of their elderly parents, which was independent of the level of practical support they provided.

v: Why Siblings Failed to Participate in the Care for their Elderly Parents

In addition to describing what siblings did and how important their caring contributions were, primary carers were also asked to explain why their other siblings were not involved in the care of their elderly parent:

> What about those brothers/sisters who don't help with caring for your father/mother. Why is that?

Primary carers provided a variety of explanations as to why some siblings were not involved. Among the more common explanations were: accounts of poor relationships between these siblings and their elderly parents; practical difficulties that arose because these siblings lived too far away or were occupied by employment; and admissions that these sibling were simply not prepared to help:

> My sister is very easy huffed; always has been. It was about two weeks after my father's death and she was supposed to come to Mum's (*house*). But she no arrived and has no been since. There's no been any row or anything; but she's taken off about something and just doesn't come round. Carer 117

> Basically because he lives so far away and he has a busy business life. He has to travel all over the country. My brother bought the house (*under Right to Buy legislation*) with us (*for their mother*) and is splitting the cost of the shower. So he's all right like that. But he's too busy with his work. Respondent 138

Aside from the rationale that primary carers provided, what is interesting here is that some primary carers rated a particular reason as legitimate while other primary carers rejected it. Comparison of the quotation above and that below illustrates this point:

> You tell me! You can come down from his place in an hour and ten minutes. I think it's basically that he's married with a family and I'm not. So, in his eyes I've no commitments and nothing else to do. They, (*brother and his wife*), tell me they don't know how I cope; that it must be hard for me. But then when I ask them for support, there's always some excuse. When they do come, they're down for an hour and a half; it's like a duty visit. Actually, hen, it's when they're (*mother and father*) in respite that we see more of them: I think it's because it looks better..Verbally, Dad's been aggressive to him (*brother*) too, so he knows all about that (*father suffers from dementia*). But he still doesn't offer to help. There was one weekend, my Dad put me out of the house. Well, he's always putting me out of the house (*even though respondent is purchasing the property under Right to Buy*). And this time I went. I just had to go and walk; I had to get away. Anyway, Mum had to phone the emergency social worker because they can't do anything without help and she didn't think I was coming back after the row I'd had with my Dad. So she phoned for help; to get someone in to toilet them and that. But no one came; they just said to phone back in a few hours if I still hadn't come back. Mum just had to sit there and wait. But my brother knows all this. It doesn't seem to make any difference. Carer 136

Carer 138 made excuses for her brother in terms of his job and emphasised that he contributed financially to their parent's support and was grateful for such support. Carer 136 on the other hand was openly critical of her brother and his wife. In her opinion, her brother made a selfish decision by not being prepared to participate in the care of their very physically disabled mother and demented father; even when the management of their parents' care was falling into crisis. Such refusal had serious repercussions for the care the respondent was required to deliver and she felt a lack of moral support.

The quotation below however combines both these viewpoints. It reveals that the carer was aware of the impediments his brother faced in assuming responsibility for the care of their father: that the quality of his brother's relationship with the father had been strained and that his brother had a high pressured job in which remuneration was dependent upon sales and target figures. Nevertheless, the carer still felt that his brother abrogated his filial duty:

> They, (*father and brother*) fell out; a long time ago. After that, my brother went to Australia: he didn't stay long mind, he came back after a couple of years. But they didn't start talking again until maybe three years ago. They didn't speak for 20 odd years. And now, he, *(brother)*, says he's not got the time. But I think he could at least visit him. He does travel a lot with his job; he's a sales rep and works for all these different companies on commission, but sometimes I know he's home for a month or so, but he never goes in. I've tackled him about it like; two or three times now. But he says: "No, no I'm too busy. I haven't got time to go down there. You can do it. You're retired; you've nothing else to do all day." I keep going on to him *(brother)* about being a poor pensioner and not being able to afford the petrol every day *(carer lives about 7 miles from elderly father)*. But he takes no notice. We haven't fallen out about it or anything...and it doesn't help that his wife doesn't get on with him (*father*). Although she works as well. She's one of these people, she'll no speak to you; she'll just sit there. And my father doesn't like her at all for it. But I think he (*brother*) could do more.
> Carer 114

This example reinforces the point that while the non-involvement of certain siblings was accepted with resignation by some of the primary carers, in other cases it remained an issue of controversy. The study did not attempt to measure the stress under which primary carers operated. It makes logical sense to suggest

however that the more burdensome the primary carer's load, the greater their need for support. Indeed, it was when carers were having difficulty fulfilling their parents' care needs or demands that they became most critical of the behaviour of their siblings:

> I resent the fact that he doesn't help (*with mother and father*). He's no critical and I suppose if I push it he'll come down, but only when things have got to a head (*between respondent and father)*. I think he thinks he's got a wife and family, I don't, and so it's up to me. Actually, they do nothing and when they do come down they make work because you end up having to cook for them or wait on them. They don't think to say: "Get away out for a few hours, we'll look after Mum and Dad for a couple of hours."
> Carer 136

This can result in conflict between primary carers and their siblings and even a breakdown in their relationship:

> She (*sister*) doesn't phone now or anything. And I hardly ever see her. If they do come to Mum's and they see our car outside, they'll wait until we go before they go in to see Mum. There was a row when my brother and his wife told her (*sister*) what I had said once about them not helping.
> Respondent 142

To recap briefly here, while primary carers pointed towards geographical distance, employment and the poor quality of relationship as reasons why siblings were not assisting in the care of their elderly parent, they also began to provide their reactions to their siblings' lack of involvement. The next series of questions therefore asked them about several aspects of their reactions to their siblings' involvement and non-involvement in a more direct fashion.

vi: Fairness and the Organisation of Filial Care

Carers were also asked:

> How fair do you consider the present arrangements for looking after your mother/father to be in terms of what you do and what your brothers/sisters do?

Interestingly, over half of the 16 carers with any siblings (56%) made a superficial indication that the care arrangements were fair in term of the division of responsibility. More detailed review of the quotations however revealed certain reservations on the part of the primary carers:

> I'm quite happy about it. I don't mind doing it for my Mum; I don't think it's unfair. Mind, sometimes I think my sister should go to see her (*mother*) more often. Admittedly, Mum's become more awkward over the past year or so; the trouble we have trying to get her out of the house and that! I suppose that's the only thing I get annoyed about.
> Carer 109

> It doesn't really worry me that he (*brother*) doesn't help; but I do think he could spend more time with my mother. We've talked about the fact that there's going to be a time when she can't cope on her own at home. But we've come to no conclusion about what we'll do. I told my brother that Mum had been going on about going to stay with him and his wife and they were supposed to be having her for a few days. but they cancelled at the last minute! They booked up somewhere for themselves apparently! She never goes down really (*to brother's home)*. I think it's just duty visits with him now.
> Carer 138

In other words, primary carers' expressions of fairness were often contradicted by their subsequent statements. The care management arrangements they described as "fair" were amplified in terms that made it clear they were actually experienced as unfair. This contradiction was echoed by another feature of the carers' responses: a rejection of the very concept of fairness in the evaluation of filial care:

> We, *(carer and wife*), don't think of things like that. If we weren't living here and it was the brother who was the nearest then he'd be doing it. Nobody bothers about what they (*siblings*) do (*for the elderly parent)*. We don't think like that.
> Carer 126

In other words, some carers were unable to question distributive justice within the family and to apply the notion to their evaluation of the organisation of filial care for aged parents. These carers presented themselves as passive players in a family performance dominated by circumstance and lack of choice rather than preference.

In direct contrast to such carers however were others who made clear expressions of dissatisfaction with regards to the organisation of filial care. These carers described a gamut of negative emotions:

> I get angry about it. I'm not expecting my brother to do anything like what I do; I'm the one who's living here. But I do think he could be more supportive. Like I turned diabetic three years ago and he's never once asked me how I am. It's the same with Mum and Dad. he never comes in and says: "Well how are you? How have you been this week?" It's always what they've been doing; how they are; like we have no life. It's unfair because he's able to lead his life and he's no prepared to give me a wee bit of life. They're his parents as much as mine...and then at times it's the older brother syndrome. You know, I'm so used to him not wanting to help that if something happens I just go ahead and sort something out. But he'll come down and say: "You should have asked me; I'm the older brother."
> Carer 136

A theme which runs through each of these three quotations is the carers' inability to get any respite from their caregiving, even when they take a physical break from their care responsibilities. The burden of care is omnipresent and it seems that siblings are the only people whose caregiving might provide an adequate substitute and thereby offer an emotional as well as physical reprieve.

vii: Debating the Organisation of Care with Siblings

The next step in the interview was to see whether or not primary carers and their siblings discussed the filial care of their elderly parents. Specifically, carers were asked:

> To what extent do you and your brother(s)/sister(s) discuss how your mother/father might best be cared for?

Of the 16 carers with any brothers or sisters, half replied that they did discuss their elderly parents' care needs with their siblings and half replied that they did not. Of those who did not enter into any discussions with their siblings, a variety of explanations were provided as to why this was the case. For instance, some carers

stated that they didn't discuss their parent because it would not achieve any change in behaviour on the part of their sibling(s):

> Not at all really; there's no point. Sometimes I'll get fed up and phone him (*brother*) to go down, but he never does, really. If he's (*father*) ill, I'm down there twice a day and then you feel as if your life's no your own. At this stage, at 89, you just wait for the phone call because the home help can't get in or something might have happened. But he's (*brother*) not really interested; he lets me get on with it.
> Carer 114

Other carers said their lack of discussions reflected the fact that their siblings simply were not involved in caring for their elderly parents for whatever reason:

> Not at all really. They hardly ever write, *(both sisters have emigrated)*. And when my youngest sister phoned, she was quite abrupt with us on the phone. You see, they speak to Mum and they wouldn't know there was anything wrong.
> Carer 116

> I don't. Sometimes, if something needs doing I'll have to talk to him. But all he ever says is: "OK: Just go ahead. Whatever you think."
> Carer 129

For the carers who did discuss their parents' care needs with their siblings, there was not one example of such discussions being either regular or structured in any way:

> My other sister does most of that; the talking. The rest of us don't really talk about her. We moan to one another like, but we just have a laugh about it. We just think it's because she's getting old.
> Carer 126

> Yes, when I see him, which isn't very often. But he can't do very much; he has his own worries. So he couldn't do anything.
> Carer 124

These results are particularly interesting in the light of the fact that so many primary carers had previously expressed reservations about the "fairness" of the filial care received by their elderly parents. Matthews and Rosner (1988) found that carers' perceptions of "unfairness" regarding filial contributions led to conflict and occasional withdrawal from care provision. While there was no evidence to

suggest that any of the carers interviewed had previously withdrawn or temporarily refused to care for their parent because of outrage about their siblings' contributions, it was nevertheless apparent from their responses that despite their initial protestations of fairness, many of them were sorely aggravated by their siblings' ability to refuse, or to limit, their participation in the care of their parents.

vii: Future Care Needs and Increasing Caring Contributions

Finally, carers were asked:

> If it became necessary, how easy would it be for you to increase your contribution in helping your father/mother?
>
> and
>
> What about your sisters/brothers? How easy would it be for them to increase their contribution in helping to look after your father/mother?

The main intention of these two questions was to investigate carers' assessments of their own and their siblings' future capacities to care. A secondary aim was to probe further into carers' evaluations of whether siblings could or should increase their caregiving.

The responses reveal that very few carers felt able to increase their caring contributions without reservation. Any such increase on their part was largely contingent upon the elderly parent taking up residence with them. More specifically, five of the 18 carers replied that they could not possibly increase the amount of care they provided their elderly parents:

> I think I'm doing all I can. I really can't do any more. When I come away, I always take a piece of paper for what he needs and I take it the next day. I mean, he wants for nothing; he's (*got*) the home help and plenty of food. I make sure of that. And my daughter's very good. When I was in hospital, she did what I do. No, I don't see how I could do more.
> Carer 114

> I don't think it would be fair on my own family to do any more. I'd have nae time for my own children and grandchildren. I think I'm doing all I can at the moment.
> Carer 117

A further seven carers replied that they could increase the amount of care they provided, but only with difficulty:

> Well, no-one knows how much inner strength they've got. I suppose I would go on, as long as I'm able. Now she's going to day care - she's been going for about six weeks now on a Monday - now she goes to that, I go in and see my neighbour for a coffee and a chat. I enjoy that. My husband makes me go out occasionally; just to get away from it. But I shall go on as long as I can. But if I find I'm breaking down in tears two or three times a week, then I'd speak to the social workers to see what was available.
> Carer 100

> Well I would just have to do it. Something would suffer; in your own life I mean. But that's families.
> Carer 101

Three carers said that the only way they could increase the care they provided their parents, involved their parent moving in with them; an eventuality which, although anticipated, was not awaited with any enthusiasm:

> I don't think I could really increase what I'm doing. My husband says it's up to me but I would have to bring her here and I'm hoping I don't have to do that. That's what at the back of my mind. I'd have to have the bed down the stairs and then it would stop you being able to have your own friends back and we have company round a lot.
> Carer 129

One carer replied that he didn't know whether he could or could not increase the care he provided his father. This meant that only two carers stated they could, unequivocally, increase their caring contributions with ease:

> If he did deteriorate at all, we would have him here. We have an extension to the house with a toilet and it's own bedroom and he would have that. Actually, we wanted him to come when my mother died, but he wouldn't move. He wanted his independence, I suppose.
> Carer 141

By way of stark contrast, of the 16 carers with any brothers or sisters, half stated that their siblings could increase the help they gave their parents should it become necessary. The problem was, however, that these siblings would probably refuse to do so. In other words, in the opinions of the carers, increases in the amount of care provided by siblings were contingent upon their willingness rather than ability to do so:

> He just wouldn't. I don't think he would even consider it. If something happened, I mean to me, then the social work department would just have to take over. Mind you, he (*brother*) did do it for four days last Christmas. You know, there's no cover over Christmas and so I was down there at breakfast, lunchtime and doing his tidying up. So I phoned him (*brother*). I'd had enough. I couldn't do anything over the holidays; not even have a proper drink because of driving down so early the next morning. So I phoned him, (*brother*), and he took over for four days. He wasn't too pleased but he did it.
> Carer 114

> I don't think he will ever help at all; he's not that way inclined. He doesn't like people when they're ill. He couldn't even go in and see dad when he went (died).
> Carer 129

There was a considerable disparity between carers' assessments of their personal ability to do more compared to their assessments of their siblings' ability to do more. Of course, as the discussion has already demonstrated, both respondent groups recounted tales of unequal filial contributions in the organisation of family care. Perhaps it is not surprising therefore that carers considered it easier for their siblings to increase their caring contribution than it was for themselves. They considered their siblings' lives to be little disrupted by the care needs of their elderly parents, whereas their own lives were considerably affected.

Summary and Conclusions

This chapter has been based on the premise that the orthodoxy surrounding "unshared care" requires conceptual challenge and empirical enquiry. Conceptually, if one accepts the predominance of "primary" carers who act alone and remain unsupported by other relatives, then understanding why and how other

family members avoid caregiving responsibilities for frail elderly kin furthers understanding of the familial division of labour, as well as the operation of distributive justice within the family. On an empirical footing, North American research has revealed that "primary" carers over-estimate their own caregiving activities yet under-estimate those undertaken by other relatives.

Because the bulk of research which promulgates the unshared care thesis depends upon accounts furnished by self-defined "primary" carers, this chapter began with an overview of the identity of carers as detailed by elderly care receivers. The data revealed that over one third (36%) of all elderly participants (over half of those participants who received any family care whatsoever), had more than one family carer. This was a very significant result and clearly contradicts the orthodoxy that care is rarely shared within the family. From the elderly participants' perspective at least, therefore , the provision of family care was not experienced in terms of a single carer/care-receiver dyad. Furthermore, the results revealed that there was very little numerical difference between elderly participants' nominations of sons as second carers as opposed to daughters: 29 per cent of relevant participants identified a daughter (i.e., excluding the 22 elderly people who received no family help whatsoever), in comparison to 26 per cent who nominated a son.

Identification of second family carers necessitated analysis of the caregiving "load " they respectively assumed. The data demonstrated very clearly that the scope of support provided by other, secondary, carers was very limited and reserved for one or two tasks. Also of importance, the analysis uncovered virtually no evidence of shared care when spousal care was the main form of family assistance. Even though elderly participants identified second (and in some cases third and fourth) family carers, the distribution of the support was nevertheless uneven. This observation that elderly people "relied" upon adult children whom they simultaneously described as providing very little practical support is something that merits further examination in family care research. At the very least it has something to say about our understanding of the "dependency" used to characterise

relations between frail elderly people and their caregiving adult children. Such dependency extends beyond the simple exchange of practical supports and emphasises the vital importance frail elderly people accord to the emotional bonds which link them with their adult children.

The 18 carers were also asked about whether and the extent to which they "shared" responsibility for their parents' care with other siblings. In establishing probable limits to such shared care, carers described how only a quarter of their siblings lived "on hand" while over three quarters were in employment (although very few had dependent children): results which reaffirmed the conclusion reached previously that any limits to shared care could not be divorced from structural factors. Little confusion existed between carers and elderly participants about the identity of main family carers: the large majority of carers agreed that they were their parents' main family carers.

The key result here was that the great majority of primary carers (15) identified a second family carer who helped support their elderly parent. In other words, although these adult children recognised the primacy of their own caring contribution, they also realised that their care was not the only family support their elderly parents relied upon. Indeed, excluding those without any siblings, over a third of carers identified a sister and a fifth identified a brother as their parents' secondary sources of family support.

Carers had very clear understandings of the nature of their siblings' caring contributions and categorised it according to three factors: the types of assistance provided; the amount of assistance provided; and how the care siblings provided fitted in with their own caring schedules or agendas. Carers' accounts revealed that they and their siblings sometimes duplicated one another's activities: not one carer, however, made any reference to such duplication being either wasteful or unnecessary. Other carers, however, described how they and their siblings undertook different tasks on behalf of their elderly parents and thus operated a system of complementarity, albeit unequally divided. Very importantly, carers

gave no indication that their siblings' care activities were undertaken on a contingency basis. Indeed, the high degree of certainty illustrated by carers regarding the nature and extent of their siblings' caring contributions suggested that some form of formal or informal arrangement existed between them.

In their evaluations, carers were generally derogatory about the importance of the practical supports their siblings provided to their parents although there were a small minority who emphasised that their siblings' efforts were absolutely essential. Rather, carers most valued the emotional support their siblings provided to themselves and to their elderly parents. In other words, the fact that primary carers did not accord much importance to the practical care their siblings provided to the elderly parents does not appear to have marred relationships between them. At some level therefore, primary carers had accommodated the unequal division of labour that existed between themselves and their siblings and were grateful for the emotional support their siblings provided.

When one or more of a carers' siblings were not involved in the practical aspects of their parents' care, however, the results were equivocal. In some cases, the non-involvement of certain siblings was accepted with resignation while in others it provided an issue of enraged controversy. The denominator which seemed to underpin the carers' reactions here was the difficulty they experienced in fulfilling their parents' care needs.

Over half of the carers with any siblings initially expressed the view that family care arrangements were fair in term of the division of responsibility. More detailed review of their replies however revealed that many carers held significant reservations about equity. Paradoxically perhaps, only half of the carers with any siblings discussed their elderly parents' care needs with them; and even then such discussions occurred only occasionally. In other words, carers failed to convey their (often strong) emotional reactions about their carer status to their siblings: they "suffered in silence" and added fuel to any emotional inferno they experienced. Finally, while very few carers (and none without reservation) felt

that they would be able to increase their caring contributions in the future should it become necessary to do so, half of those with siblings stated that their sisters and brothers would be able to increase the help they gave their parents should it become necessary.

Taken collectively, these results confirm the strength of the conceptual and empirical challenge to the orthodoxy of "unshared care". The organisation of family care is far more complicated than the analysis of primary carer activity allows. In reality, as opposed to the research setting, the provision of family care to elderly kin takes place in the context of the total variety of relationships that exist within the family network: between care receiver and a (primary) carer; between a (primary) carer and other family members; between care receiver and other family members. In order to understand the dynamics of family care to elderly people therefore, one needs to place both its conceptualisation and its analysis within a family network context. It is both important and timely that researchers now challenge the "methodological individualism" whereby analysis starts and ends with the individual. Rather, as the above conceptual and empirical investigation of secondary family carers has shown, caregiving research should use the family as the unit of analysis in studies of family care to elderly people.

7

PERSPECTIVES ON DOMICILIARY SERVICES: USER AND CARER REACTIONS

Introduction

The provision of care for functionally impaired elderly people is organised by a mixed economy of welfare in which the state has a multiple role and assigns responsibility for welfare delivery to four sectors: the statutory; the commercial; the voluntary; and the informal (Wolfenden, 1978). The precise configuration of contributions provided by each source differs over time and between residential and domiciliary support, (Johnson, 1990), but research consistently highlights the preponderance of family care over any. The social welfare system in Britain depends heavily upon efforts of the family, and most particularly female kin (Qureshi and Walker, 1989 p109). It has been estimated that family care accounts for up to 90% of the total care received by elderly people, (Walker, 1981; Abrams, 1985), while "formal" care provides a small minority of supports received. This scenario epitomises the paradox of state provision: elderly people are major consumers of public services, yet public services are minor suppliers of the care elderly people receive. Nevertheless, as major consumers of public services it is important to chart the variety and levels of formal support elderly people receive.

This chapter considers the role played by domiciliary services in the care of 57 elderly people interviewed for this study. It is the necessary precursor to chapter nine which explores the ways in which family care and formal care interact at the site of care provision in elderly people's homes. Specifically, it charts the types and levels of domiciliary services received by elderly respondents and is organised into three sections: a selective overview of the public policy rubric of community

care; the experiences of elderly participants as domiciliary service users; and an overview of the attitudes of carers towards their parents' receipt of services.

The Policy Scenario

A number of reviews catalogue the development of community care, (e.g., Titmuss, 1968; Finch and Groves, 1980; Walker, 1981; Parker, 1988; Henwood, 1990). An equally prolific literature charts its unsteady progress, (e.g., Titmuss, 1961; Henwood and Wicks, 1984; Audit Commission, 1986; Davies and Challis, 1986; Hunter and Wistow, 1987; National Audit Office, 1987; Henwood 1995): a progress characterised first by consensus and then by conflict, (Walker, 1993). The intention here is to draw attention only to those points of policy and practice which inform the remit of this study; it is not a comprehensive critique of community care.

Community care is most broadly defined as:

> ...the help and support given to individuals, including children, people with disabilities and elderly people, in non-institutional setting
> Walker, 1982 p5

Alan Walker's definition emphasises the setting of care and overlooks the source of care. Tension between the source and setting of "community" care however is highly significant: it highlights a strategic contradiction whereby the twin axioms of policy operate in fundamental opposition to each other (Henwood, 1990, p18; McIntyre, 1977). Concern to facilitate the preferences of frail elderly people to remain in their own homes for as long and as independently as possible, (the setting of care), has attracted widespread political consensus. By way of direct contrast however, community care has been conceptualised in terms of providing a cheaper alternative to expensive residential care. In official documents at least, it has not often been presented as an add-on cost in the development and promotion of a continuum of services, (see Rao, 1991). The savings offered by a strategy of community as opposed to institutional care therefore have been predicated on the

assumption that community care refers to care by the community rather than care in the community (DHSS, 1981 para 1.9):

> Publicly provided services constitute only a small part of the total care provided to people in need. Families, friends, neighbours and other local people respond to needs which they are uniquely well-placed to identify and respond to. This will continue to be the primary means by which people are enabled to live normal lives in community settings...this is as it should be, ...the first task of publicly provided services is to support and where possible strengthen these networks of carers.
> Sir Roy Griffiths 1988 para 3.2

In other words, the economic policies and political ideology of the family which underpin the practice of community care have combined to render community care a synonym for family care and most particularly the unpaid labour of wives and daughters (Baldwin and Twigg, 1991). Rather than extending the provision of social services within the community, the burden of care responsibility has fallen disproportionately upon family carers. Consequently, there has been a disparity between the rhetoric and reality of community care; a disparity which relates to the source and setting of care dichotomy and a disparity which underpins its renunciation, (e.g., Audit Commission, 1986).

In addition to this strategic contradiction, community care has been beleaguered by a variety of operational weaknesses including: an absence of clearly stated operational goals; confusion and controversy concerning resource allocation mechanisms; and a lack of outcome measures by which targets could be evaluated, (Walker, 1982; Glennerster et al., 1990). In particular, the outcome weaknesses of community care have been identified as: administrative complexity and confusion between local and health authorities; a failure to shift resources from institutional to domiciliary support; a failure to target and plan resources at either service user or authority level; and a failure to "empower" the consumer (Hoyes, Means and Le Grand, 1992).

Despite their sheer array, these strategic and operational deficiencies only partly describe the policy backdrop to the 1988 review of community care conducted by Sir Roy Griffiths. The major catalyst to the review and subsequent legislation was a desire to stem the growth in the public subsidy of care services for the disabled via private residential care (Glennerster et al., 1990 p3). Thus Sir Roy Griffiths introduced his "Agenda for Action" by explaining:

> ...community care has been talked of for 30 years and in few areas can the gap between political rhetoric and policy on the one hand, or between policy and reality in the field have been so great.
> Griffiths, 1988 para 9.

Sir Roy's personal "agenda" in large part comprises the current official agenda for community care policy and practice. Indeed, with the exceptions of ring-fenced funding and the creation of a Minister with a community care portfolio, the planning recommendations provided in Griffiths' Green Paper have been echoed closely in the Government's 1989 White Paper "Caring for People: Community Care in the Next Decade and Beyond" (Department of Health, 1989) and thereafter in the 1990 National Health Service and Community Care Act.

The 1989 White Paper and 1990 Act were underpinned by the belief that market mechanisms improve the efficiency and "consumer" responsiveness of social care (Hoyes et al., 1992). Accordingly, the White Paper set out four axioms for policy and practice: the targeting of services to those with greatest assessed need; the minimal provision of services in the fostering of independence; responsive and flexible services sensitive to the needs of service users and their carers; and a variety of service providers in the delivery of care (Department of Health, 1989, p5).

"Caring for People" thereby contained several statements of significance for family care. Indeed, the second of its six key objectives was "to ensure that service providers make practical support for carers a high priority" (para 1.11). It stressed the role of social services in providing carers with "help to be able to manage what can become a heavy burden" and suggested that "their lives can be made much

easier if the right support is there at the right time, and a key responsibility of statutory service providers should be to do all they can to assist and support carers" (para 2.3).

Under the terms of the subsequent 1990 Act, carers' needs were to inform the assessment process and practical support was to be accorded a high priority by the purchasers of care. The 1990 Act also separated the purchaser-provider functions in the organisation of community care services. To facilitate this, although local authorities were designated as "lead" agencies, (with the sole exception of social care responsibilities for people with a mental illness where health authorities were accorded lead status), they were specifically directed to make maximum use of private and voluntary services for service delivery. Local authorities therefore now have responsibility for the assessment of need and consequent design and organisation of individual packages of care. In this way, local authorities pursue a care management rather than care provision role.

The 1990 Act also set out a new method of funding community care whereby local authorities have a single unified budget channelled via the Revenue Support Grant to cover the gamut of community care services including domiciliary, day, statutory and non-statutory residential care. The monies necessary for the latter represent the care element of board-and-lodging allowances previously funded by social security, although the provisions were not retrospective and did not apply to people in non-statutory residential care prior to April 1993 (Walker, 1993, p217).

Almost immediately after publication of the 1990 Act, criticism was levelled at the decision not to ring-fence public expenditure and at the under-capitalisation of community care services (Henwood, 1995). Specifically, the government's unwillingness to link service planning with the resource allocation process was understood to compromise the ability of local authorities to fulfil their new responsibilities and thereby jeopardised any successful prognosis for inter-agency planning (Wistow and Henwood, 1991, p81-2). In actual fact, purchasing

community care services has already reached a state of crisis in many local authorities.[1]

The provisions contained in the 1990 Act of course did not come into full effect until 1 April 1993 and during this interim period the Department of Health published several documents containing iterative guidance and key tasks for implementation. Thinking only about service users and their family carers, the first of these was issued in 1990 in a circular providing guidance to local authorities stressing the significance of involving, and taking account of the needs of, both service users and their carers in the process of assessment (Department of Health, 1990 paras 3.16, 3.18, 3.27 and 3.28). This was followed in 1991 by the publication "Getting it Right for Carers" which established a threefold strategy for incorporating carers' interests in service development: taking carers' definitions of needs into consideration and providing the services they want; incorporating flexibility, friendliness and informality in service delivery; and promoting services to carers (Department of Health, 1991). In September 1992, the Department set local and health authorities eight key tasks for implementation including establishing assessment systems and informing the public of the arrangements agreed for assessment and delivery of care (Department of Health, 1992). Finally here, the Department issued a circular in March 1993 which exhorted local and health authorities to increase the involvement of users and carers in the planning and delivery of community care services (Department of Health, 1993).

Despite this proliferation of advice and planning statements, critics of the 1990 Act reveal a high degree of cynicism. Alan Walker for instance forecasts that the Act will do little for users and carers either in terms of their involvement in the service planning process or their empowerment vis-à-vis the local authority:

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[1] At the time of writing, the local authorities of Gloucestershire and the Isle of Wight were seeking legal judgement concerning their statutory duty to purchase community care services for assessed individuals when the funding they received to do so from central government was allegedly inadequate. The rulings confirmed the obligations of local authorities to provide necessary services but stated that their ability to do so is contingent upon adequate funding.

> Professional opinions will continue to dominate...rather than determining their own packages of care, service users are apparently still seen as passive receivers of care.
> Walker, 1993 p219

Walker is sceptical about the effects of extending the service provider function to non-statutory sectors and argues that it will effectively limit statutory services to the most severely disabled. Walker also points out that the Act contains no specific proposals for ensuring that the needs of carers are taken into account in planning services and is highly critical that it fails to recognise the potential conflict of interest between carers and those who receive care. He argues that the assessment process, especially the inability of users or carers to appeal against the outcome, will limit user and carer choice in services delivered and concludes that the Act provides no practical means whereby the involvement and empowerment of users and carers in the care management process is improved. Rather his analysis suggests:

> ...the measures currently being implemented are directed at cost-containment and the run-down of public social services.
> Walker, 1993, p224

Henwood and Wistow make the observation that in the arena of community care it is vital never to confuse policy intentions with policy outcomes, (Henwood and Wistow, 1991, p84). Such admonition is very pertinent: the real support that family carers are likely to receive from formal services is contingent upon the volume of assessed needs, resource allocation limitations, and professional opinion regarding the normative responsibilities of different family members. Despite these significant reservations however, recognising and assessing the needs of people and their carers, and developing and managing appropriate care is at the core of the government's stated commitment to community care. With this optimistic note in mind, it is timely to move on to an exploration of the experiences and assessments of domiciliary service users and their carers.

The Study Data

a: The Elderly Service User Perspective

Receipt of Services: Referral and Longevity

The 57 elderly participants were asked to describe how they came to the attention of the organisers of domiciliary services provided by the SWD and to explain why they were referred. The results reveal that not one respondent attributed their receipt of services to the activities of a social worker. Rather the data highlighted the importance of health professionals in the referral process. In total, **three quarters of participants were referred to the SWD by health professionals: 47 per cent by their GP or another member of the primary health care team ; and 28 per cent via hospital discharge procedures.**

> I started with it after my stroke: the physiotherapist and occupational therapist came here to see if I would be able to manage myself when I got out of hospital. And it was a fortnight later I came home and she *(the occupational therapist)* had fixed up all the different services I would require. And then I got a visit from the home care people.
> Respondent 102

> Three years ago come July the doctor referred me to the social work department when we discovered that *(husband)* had dementia.
> Respondent 104 (Interview by proxy with wife)[2]

By way of direct contrast, **only one elderly service user had approached the SWD personally for assessment and assistance. With regard to family carers, two spouses acted as referral agents, whilst seven daughters did the same for their parent. Of these seven daughters, five were the respondents' main carers. Interestingly, not one son acted as a referral agent.**

The dominance by health care professionals of the referral process has important strategic and operational planning implications. The SWD "owns" the home care

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[2] Chapter two explains why it was necessary to conduct this interview by proxy

budget and will accept referrals for services from any agency or individual. Despite such ownership however, health care professionals effectively acted as gatekeepers to services their own agencies did not (usually) have to finance. They determined the caseload for assessment by the SWD and generated in large part the potential demand for essentially non-medical domiciliary services. Of course, hospital discharge policies and the public health surveillance duties of General Practitioners mean that such referral behaviour is to be expected; nevertheless, the magnitude of these referrals highlight the difficulties that local authorities face in controlling demands made upon its domiciliary services.

Respondents were also asked to explain why they were referred to the SWD. Table 7.1 below reveals that the most common reason was an admission on the part of elderly participants that they could no longer cope at home, either on their own or with their spouses:

> It was because I couldn't cope at home; not after my operations.
> Respondent 118 (Double Amputee)

> We were both unable to do anything. I couldn't look after my husband and he couldn't look after me. And our daughter is out at work all day.
> Respondent 136

Eight respondents simply did not know why they were first referred. Such ignorance might have reflected failing memories on the part of these respondents or be attributable to the prolonged periods many respondents used community care services (see below). Nevertheless, they are noteworthy in the light of the introduction of care management and its stress upon the importance of involving service users in the decision making process:

> I don't know why. When I need anything, my neighbours sort it out for me. I tick over very comfortably here.
> Respondent 122

Also noteworthy in table 7.1 are the seven elderly service users who indicated that domiciliary services were first introduced on behalf of their now dead spouses:

> Mrs ... (*wife, now dead*), had a heart attack and it was after she came out of hospital that a supervisor from the home help association came round to see us, because of her. It's gone on since then.
> Respondent 141

This result suggests that domiciliary services were "passported" within elderly households: upon the death of the original "client", the widowed spouse assumed usership. Such a transfer may have resulted from the inherently indivisible nature of domiciliary services delivery; the provision of home help was likely to benefit both parties of a married couple even if only one was the official service user. In this way, the boundaries of service receipt became blurred. Nevertheless, it would be interesting to examine the procedures which accompanied such transfers and the types and levels of services delivered:

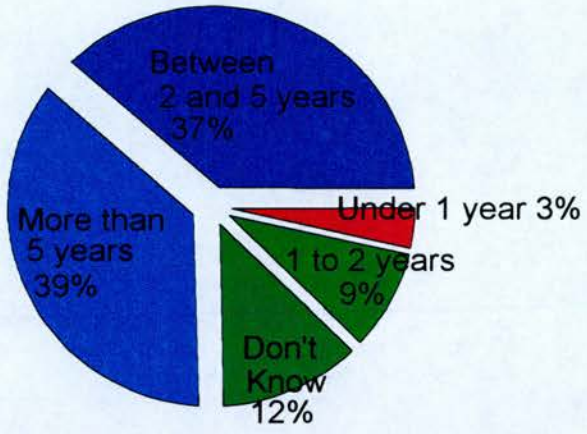
> I used to get three hours *(of home help)* when ... (*wife*) was here (*alive*), but they cut it down after she went (*died*). I don't know why; because the services were stretched in the area I suppose.
> Respondent 142

Table 7.1: Elderly Participants' Reasons for their Referral to the SWD

REASON FOR REFERRAL	N=57 (%)
Respondent's admission they were unable to cope	22 (39)
To convalesce after operation/illness	8 (14)
Services contd. after death of spouse	7 (12)
Child's concern and inability to provide sufficient help	7 (12)
Spouse unable to provide sufficient help	3 (5)
To give carer respite	2 (3)
Don't Know	8 (14)

The most notable feature about the length of time elderly participants had received domiciliary services was its longevity: **almost 40% had been service users for five years or more**. Whilst this in itself was not terribly surprising, it nevertheless highlights the importance of regular reassessment in the care management process. Indeed, it would be very interesting to ascertain the reassessment experiences of those service users of five years duration or more in a future research project. Certainly the anecdotal impression gained during these interviews was that the great majority of respondents were unaware of any formal reassessment ever having taken place.

Chart 7.1: Length of Domiciliary Service Receipt



57

The Types of Services Received

It is sometimes easy to forget the motives that underpin research. An important motive of this study concerned a desire to identify the significance of domiciliary services in the lives of frail elderly people. The following quotation provides a glimpse into the range of domiciliary services received by one elderly participant. These words eloquently express the importance of domiciliary services in the lives of frail and disabled elderly people and provide a fitting introduction to the more empirical discussion below:

> I've had the district nurse since 1982; but they'll finish up next week-end when the home helps take over. They wash and dress me and give me a bath; or up until recently they have. The daughter does that now...We're no allowed that community alarm thing because there's the two of us. If there was only the one, we could have got it. They gave me the ramp outside and put in the toilet that washes and dries you, and they put in the bath chair...The home help I have, she comes in at breakfast and sees to that and then she tidies around the place. If she no manages to do what she should do, she'll stay the extra quarter of an hour to finish off. I've had her for nine years now, so she's into a routine... Then she comes back later on to put me on the toilet and do the lunch. And then she comes back at tea time and gets us a snack. We go to day care twice a week. The minibus collects us and brings us back. Well it gets us out; you need to meet other folk...We (*respondent and her husband*) love respite.
> Respondent 136

More quantitatively, table 7.2 below distinguishes between the overall receipt of domiciliary services and those delivered to elderly respondents with "high" levels of functional impairment; an ADL and IADL score of 11 and over. The most striking feature of the results was the predominance of home help receipt: **95 per cent of all respondents received a home help.** Such predominance of a single service has planning implications in terms of the SWD's development of care management procedures and practices. At the time of fieldwork, home helps were direct employees of the SWD. These results therefore confirmed that the delivery function of the SWD remained the most conspicuous characteristic of community care. The future management of the home help function therefore, if the SWD accords with the strategic aims of government, represents a major area for change. In particular, the way in which any transfer of the home help function into "private" hands is orchestrated, the "ownership" of a home help service, and the issue of quality assurance will constitute key issues of concern for SWD domiciliary programme and service managers.

Also noteworthy below in table 7.2 is the high proportion of service users whose homes have been adapted in order to mitigate the effects of chronic ailments or disabilities upon functional independence: **75 per cent of all respondents and 85 per cent of high dependency respondents have had some home adaptation.** In most cases, such "adaptations" simply involved attaching handrails to a bath or

raising the seat of a toilet; in others cases though, major internal adaptations had been made or sheltered housing provided:

> They moved me here a good few years ago; since my double amputation. I can get around in the chair (*wheelchair)*; all the cupboards are low down. Everything has been specially adapted.
> Respondent 118

> They put a handle on the side (*of the bath*) and a (*bath*) seat to sit on; and they put rails on the stair for the wife (*now dead*), but they help me now.
> Respondent 132

> I have a lift to get me downstairs. It's a vertical lift that goes from the dining room into the other bedroom. The social services gave me a grant of £5,500 to do it with.
> Respondent 139

A final note on house adaptations is that although they can make a significant difference to the independence enjoyed by frail elderly people, there was evidence that some elderly people did not know how to use the equipment supplied to them:

> Last year they gave me a proper chair for the bath. I think they thought I wasn't grateful when it was all being sorted, but I'm frightened about it. She said they'd be back to sort someone out to show me how to use it. That was a year ago and I've heard nothing since.
> Respondent 134

In addition to improving respondents' physical environments, the table below also highlights the extent to which community care services are devoted to the social and psychological well being of service users. **Almost half (47%) of all respondents, and 85 per cent of high dependency respondents, attended day care facilities run by the SWD**. Transport by minibus is invariably provided to those who attend day care; a practice which was of obvious importance to those 82 per cent of respondents with high dependency levels who used this service. Given their level of dependency, very few elderly participants availed themselves of the dial-a-ride scheme operated by the local authority although a small number of respondents did mention this scheme by name.

Table 7.2: Domiciliary Services Received by Elderly Participants

SERVICE	TOTAL N=57 (%)	HIGH DEPENDENCY n=37 (%)	% Total Services t High Dependency Participants
Home Help	54 (95)	35 (95)	65
Chiropodist	45 (79)	31 (84)	69
Adaptations to Home	43 (75)	31 (84)	72
Transport	28 (49)	23 (62)	82
Day Care	27 (47)	23 (62)	85
Free TV Licence	27 (47)	24 (65)	89
Community Alarm	21 (37)	16(43)	76
District Nurse	16 (28)	14 (38)	88
Wheelchair	15 (26)	15 (41)	100
Meals on Wheels	11 (19)	9 (24)	82
Respite Care	10 (18)	10 (27)	100
Auxiliary Nurse	6 (11)	6 (16)	100
Specialist Therapy	6 (11)	6 (16)	100
Hospital Day Care	5 (9)	4 (11)	80
Incontinence Laundry	2 (3)	2 (5)	
Foster Care	-	-	-
Evening Care	-	-	-

A key feature of table 7.2 above is that it provides an overview of the distribution of domiciliary services according to level of disability: the second column details how many high dependency participants received each service while the third column provides these figures as percentages of the total numbers of participants in receipt of each service. With the exception of home helps, at least two thirds of the different types of services received by the elderly participants are received by those with high dependency scores. For instance, of the 21 participants whose telephone lines had been connected to the community alarm scheme, 76 per cent had high dependency scores. **At first sight, such data suggest that the domiciliary services were effectively targeted to those participants with greatest needs.**

In order to provide confidence in such a conclusion however, these service receipt figures should be directly juxtaposed with elderly respondents' accounts of their care needs as revealed in chapter three. When the two sets of results are read together, the data place a question mark over the notion of effective targeting. For instance, **almost three quarters of all elderly respondents (42) stated that they were either unable or found it difficult to prepare a main meal for themselves, but less than a fifth (19%) received meals on wheels.** Furthermore, even though respite care was only provided to high dependency respondents, the overall rate of provision was very low amongst all respondents, (18%), as was that of auxiliary nursing, specialist therapy (including occupational therapy), and most particularly the foster care scheme and evening "tuck in" service. In other words, domiciliary services did not reach all those elderly people with care needs.

The notion of targeting domiciliary services places emphasis upon the outreach efforts of the delivery agency. Its operational corollary however concerns take-up on the part of (prospective) service users; behaviour which is affected by such things as dependency type, attitudes to services, and availability of suitable family carers, (see discussion in chapter seven). For instance, there was evidence to suggest that some elderly people either refused or did not perceive a need for domiciliary services because of the presence of a family member:

> ...I don't want to go to those other things..the day places. I've seen so many deteriorating when they go there. I suppose really it's because I have my daughter, that's why.
> Respondent 124

> I've never thought about it (*day care*) because I have my husband for company.
> Respondent 139

> (*Re respite and day care*) I'm happier here. My daughter-in-law is always on to me to come along there, but I prefer it here. And I think my daughter is hinting for me to go there to stay. Oh, she's very good but she has to be the boss, like! I suppose I wouldn't mind, but I'm quite happy here.
> Respondent 146

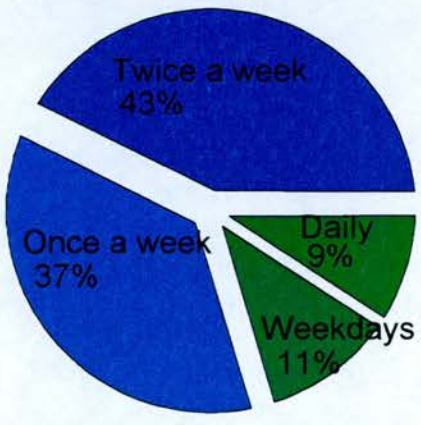
The most appropriate conclusion to draw at this point therefore is that although the coverage of domiciliary services among participants was scant, there was no evidence whatsoever of any mis-servicing in terms of allocation: those domiciliary services which were received went to elderly participants with the highest dependency levels.

The Levels of Services Received

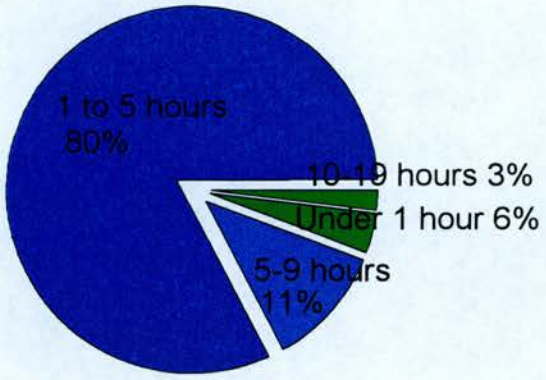
Respondents were also asked about the levels of services they received. The first set of pie charts below concern the frequency of home help service received by the participants and the amount of home help time allocated to them. They reveal that despite near universal receipt, the actual levels received by the elderly participants were low. **Over a third (37%) of respondents saw their home help once a week only, while a further 43% saw them two or three times a week. This was reflected in the home help hours allocated to respondents: 85 per cent received less than five home help hours a week.**

Chart 7.2: Elderly Participants' Receipt of Home Help Service

a: The Frequency of Visits : n=54



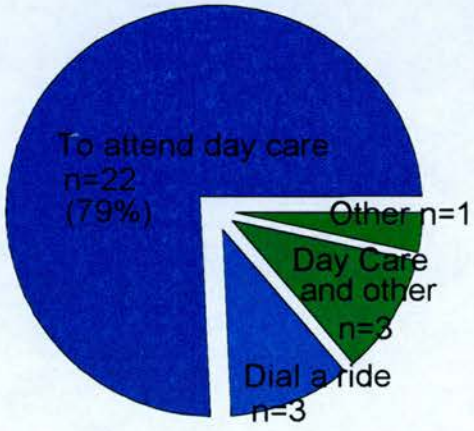
b: Weekly Home Help Hours Received (N=54)



Elderly participants' use of transport facilities offered under community care arrangements by the local authority resulted in large part from their attendance at day care: **79 per cent availed themselves of minibus facilities in order to get to day care establishments.**

Chart 7.3: Reasons for the Use of Transport Provided by the SWD

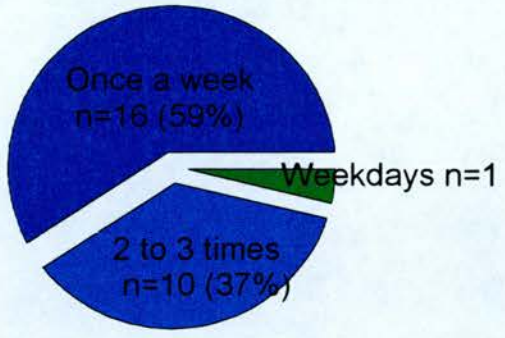
N=28



The two pie charts which make up chart 7.4 below illustrate participants' attendance at day care centres. Over half (59%) of the 27 participants who attended day care did so once a week only, although it should also be noted that the very large majority spent the whole day at the centre when they did attend.

Chart 7.4: Elderly Participants' Attendance at Day Care Establishments

a: Frequency of Attendance Frequency: (N=27)



b: The Hours of Attendance

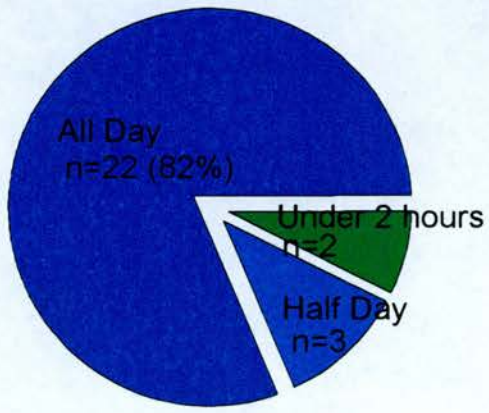


Chart 7.5: The Frequency of District Nurse Visits

Frequency: (N=16)

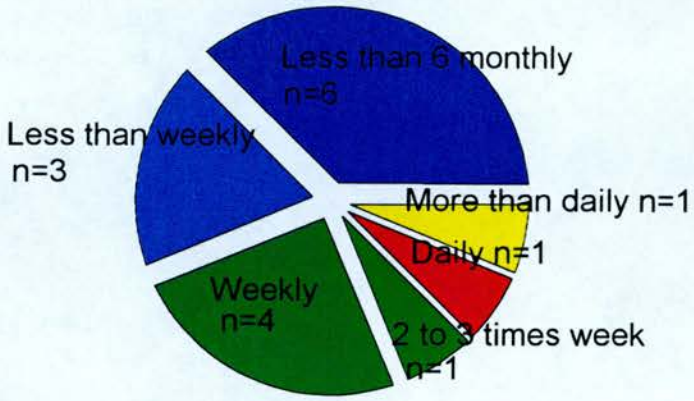


Chart 7.6: The Frequency of Meals on Wheels

Frequency: (N=11)

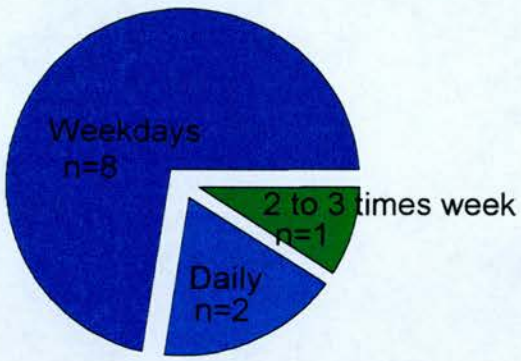
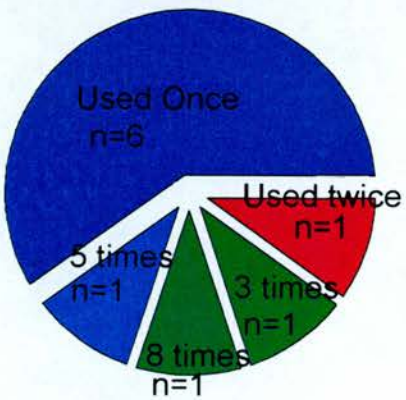


Chart 7.7: Elderly Participants' Attendance at Respite Care Facilities

Frequency: (N=10)



The Adequacy of Service Levels

Elderly care receivers were asked two questions about the adequacy of services they received from the SWD. The first concerned the perceived adequacy of services they already received while the second question was designed to identify any subjectively defined unmet need:

> First of all, thinking about the levels of services you receive from the SWD, do you think you receive too much, too little or about the right amount of each service?
>
> and
>
> Can I just check, do you feel that you need any other service or help from the SWD, I mean in addition to those you already receive?

Table 7.3 below reveals that a sizeable minority of home help and day care service users thought the help they received was "too little". (Of course, respite care, specialist therapy and hospital day care services also have high levels of perceived inadequacy, but the small numbers involved preclude any useful analysis). **Over a third (37%) of home help recipients thought they received too little, while just under a third (30%) of elderly respondents who attended day care wanted more provision.**

Table 7.3: The Adequacy of Services Received

SERVICE n	Too Much n	Too Little n (%)	About Right n (%)
Home Help 54	-	20 (37)	34 (63)
Transport 28	-	4 (14)	24 (86)
Day Care 27	-	8 (30)	19 (70)
District Nurse 16	-	2	14
Meals on Wheels 11	-	2	9
Respite Care 10	1	4	5
Auxiliary Nurse 6	-	2	4
Specialist Therapy 6	-	3	3
Hospital Day Care 5	-	2	3
Incontinence Laundry 2	-	-	2

The allocation of domiciliary services is, of course, governed by financial limitations. Some elderly respondents were aware of the financial constraints faced by the SWD and subjugated their personal needs according to an economic rationality argument:

> I started off with six hours *(of home help)* a week in 1981, and now it's down to two. It's been gradual, when they've cut it. Mind you, we understand why; there's no money and that. We understand that we have to take our cut. I suppose we're lucky to get a home help at all.
> Respondent 139

A common complaint among respondents who replied that they received "too little" home help was that this inadequacy resulted from cuts in service hours:

> When I first took this *(stroke)* I wasn't too bad and I had a home help three times a week. Now I'm worse, I only get a home help once a week! They've really cut that down.
> Respondent 125

> It used to be an hour in the morning and then again in the evening, but they cut it down to half an hour each time. The home help asked her (*the home care organiser*) what if she couldn't do it all in the half hour and the manager told her she was to leave things lying. So now I have to force the food down to get it finished in the half hour so she can clear up. I would like to see them get a little more time (*home help*) even if it was just another quarter of an hour. But it's all to do with expense you see. You see, if the dishes aren't done, they have to lie (*in the sink*). And I have to rush my dinner to get it down in the half an hour. And she (*the home help organiser*) said: "The girls said to me they've not that much to do at night for your tea." And I told her: "That's not true". And I asked the girls and none of them said that...It's all to save money, hen.
> Respondent 148

The need to cut services is not at issue here. Nevertheless, the quotations above raise an important issue regarding the incorporation of elderly service users' expressed needs and opinions into programme and service-delivery planning and decision-making. Fundamentally, the quotations revealed that elderly service users were simply informed that their allocation of home help time was going to be reduced: there was no consultation procedure and apparently no systematic evaluation of either care needs or the impact of such reductions. Succinctly, decisions about service levels were taken in isolation from any discussions with service users and then imposed on service users: an extremely rigid model of managerial practice which contravenes the ethos about relations with service users and carers promulgated in the 1990 legislation Moreover, it is highly probable that these service cuts were implemented alongside declines in the participants' functional abilities. As the first quotation above reminds us, chronic ailments invariably deteriorate over time and such deteriorations usually exacerbate any difficulties in functional capabilities. As the participants suggest above, therefore, although they understood the reasons for service cuts, their quality of life declined in disproportionate measure as a result.

Finally on this matter, respondents identified home help organisers as their bureaucratic links in the decision to cut services. The descriptions given by the elderly participants suggested that the implementation, (if not determination), of the care management function resided at operational, as opposed to specialist, level. From the service user perspective, there was no appreciation of any

separation of planning from provision; participants were not aware of any purchaser/provider split. Indeed, conspicuous by their absence in elderly participants' descriptions of how and why their home help allocations were reduced are references to any discussions one might properly assume they had with care managers; social workers or health care workers. Instead, their accounts revealed that decisions to reduce service levels were implemented, if not taken, at operational rather than any strategic level:

> They took her (*home help*) away from me for a while. The organiser came and said there was nae money. And then I saw the home help in the street, oh a few months later, and she asked me if I had my home help back. When I said no she said "Get on that phone". So I phoned them, like, and they gave me another one for an hour and a half. I was without one for four or five months, I think. It was because they were short of money at the time. It was 1991; it must have been.
> Respondent 132

Moving on to day care provision, elderly participants composed their complaints about "too little" service with reference to the brevity of the "day" spent at a day centre and their need for more company:

> It's really nice up there (*the local resource centre*). The only snag is they, *(the minibus)* keep coming later and later and it's twenty past twelve before you get there and it's time to come back before you know it.
> Respondent 120

With regard to the question about unfulfilled care needs, **over two thirds (67%) of respondents stated that they needed services or help from the local authority in addition to those they already received.** Furthermore, the data reveal that subjectively defined unmet need was particularly pronounced amongst the most functionally disabled respondents. Over three quarters (78%) of the 37 elderly participants with a "high" functional dependency score, (eleven or more), stated that they needed more help from local domiciliary services. The types of domiciliary services participants itemised in describing their unmet care needs are catalogued in table 7.4. below: its most notable feature is the request for heavy housework, including laundry, to be undertaken by home helps.

Table 7.4: Additional Services Needed by Elderly Participants

EXTRA SERVICE NEEDED	TOTAL N=38 (%)	HIGH DEPENDENCY N=29 (%)
Heavy Housework (incl. laundry)	16 (42)	13 (45)
Gardening/HH Maintenance	7 (18)	3 (10)
Day Care/Respite	6 (16)	6 (21)
Specialist Therapy	4 (11)	3 (10)
Books	2	1
Financial Help	1	1
To Be Taken Out	1	1
Personal Care	1	1

These data suggest two possible conclusions. First, fewer service users with low or medium levels of assessed functional impairment (i.e. a score of under 11), stated a need for extra or additional services than their contemporaries with high functional impairment. In other words, at the highest levels of functional impairment, domiciliary services were most likely to fail to satisfy care needs. It is relevant to note here that the SWD did not apply budgetary ceilings to individual packages of services. The actual descriptions of extra help required by elderly participants however suggest another conclusion. Participants' descriptions of additional support required emphasised tasks which fell outside the remit of home help provision. In particular, laundry and heavy housework were oft quoted care needs:

> The laundry is a real problem. I just can't get my twin tub out, it's too heavy. And I can't afford a front loader. Also if I need my windows cleaned and curtains put up, the home helps are no allowed to do that. And I fell off the step ladder that one time, but she *(the home help)* told me she was no allowed to do it. In fact, she told me that she was no supposed to clean the house because "We're (*Region*) carers now and we're only supposed to come in and see that you're OK and if you need a cup of tea". She told me I was supposed to pay someone to clean for me. How can I do that? By the time she comes in and has a cup of tea, it's time for her to go. In fact, I haven't seen her for two weeks; there's been no one here for two weeks. One time she was away for three weeks and I didn't hear anything....No, hen, she didn't tell me beforehand.
> Respondent 109

> The thing I'm really complaining about is the washing, the windows and the curtains. She's *(home help)* not allowed to do it. I feel very strongly about those things; having to pay someone myself when I have a home help. It's not fair to these women, the home helps...they're happy to do a wee bit of washing! I mean, we are the sufferers; the pensioners. And it's all wrong... I mean, I can't even brush my hair unless I'm sitting down, let alone wash my windows.
> Respondent 127

It is important to note that the job descriptions of home helps in the SWD had undergone significant change in the months preceding fieldwork for this research. Home helps are now known as personal care workers and the emphasis is as much upon the emotional and social support of frail elderly people as it is the cleanliness of their homes. Furthermore, heavy housework has always been excluded from the job description of home help provision because of considerations of health and safety at work and expensive insurance premiums. The data here emphasised that what frail elderly people wanted most were those very services which were unavailable. Such a scenario contravenes the principles of the free market so keenly espoused in government policy: service "consumers" had no purchasing power; their demand failed to provide the catalyst to supply. This lack of effective demand on the part of service users means that community care operated according to the principles of a "quasi-market" in which the buyers and suppliers of services and users of services had different aims and exerted differential influence over allocation outcomes.

The two quotations below emphasise this point yet further. Unmet care needs were more to do with tasks that were outside the scope of domiciliary services than tasks which were inadequately undertaken. This raises an important point for the encouragement of a mixed economy of care provision: unmet need amongst existing service users is only likely to be reduced via a proliferation of service providers if the services those providers make available are also subject to such proliferation:

> It's the garden really. It's not so much the grass, although getting it tidied up after the council cut it is a problem, *(the cuttings are not picked up*). No, it's the little plot there. I don't know what will happen when the spring comes, really. I love my garden.
> Respondent 147

> One thing I'm badly in need of, love, is people to take me out in the wheelchair. I'm desperate you see. The secretary of the church across the way comes along every Sunday and takes me over the road and brings me back again. But sometimes I need to go down town and I have to send my neighbour.
> Respondent 118

b: The Carer Viewpoint

Interviews with the 18 carers also addressed matters concerning their elderly parents' receipt of domiciliary services. The major focus of interest concerned carers' interpretations of why their parents started to receive domiciliary services, their assessments of the adequacy of services received and their views concerning their parents' unmet care needs. The rationale for these questions was founded upon the confusion that surrounds the ways in which formal welfare agencies view and behave towards family carers (see Twigg, 1993). The intention with regard to ascertaining opinions about why elderly parents started to receive domiciliary services was to allow carers to explain whether or not their needs as carers played any part in the orchestration of domiciliary support. The purpose of asking carers to identify their parents' domiciliary service needs and then to evaluate the adequacy of levels of services allocated was to highlight whether or not formal assessments matched carers' assessments of the elderly parents' care needs.

Reasons Why Parents Started to Receive Domiciliary Services

Carers were first asked:

> Can you explain to me why your mother/father started to receive services at home from the Social Work Department?

Two carers could remember neither how nor why their elderly parents started to receive domiciliary services, while a third carer explained that the services were originally intended for his other, now deceased, parent. The most common reason carers cited, however, as to why parents started to receive domiciliary services concerned the actions of health care professionals. Twelve of the 18 carers indicated either that their parents had been to see either their GP or a practice nurse and that they had contacted the SWD subsequent to their consultation or that their parent had been in hospital and had been put in touch with the SWD as part of the discharge procedures:

> It was through the surgery nurse. As you know, after 75 they have their regular check up and Mum was bad this one time and I couldn't get her into the surgery. So I phoned up for the nurse to come here. So the nurse comes and starts to assess her about any difficulties she has around the house. So I told her about Mum not being able to get into the bath and so she couldn't have one. So the nurse said she'd get in touch with someone for us and a social worker came and had a short session with us and sorted it out. Carer 100

This predominance of health care professionals in carers' explanations as to how and why their elderly parent started to receive domiciliary care services is, of course, reminiscent of the explanations provided by the elderly respondents themselves. They emphasise yet again the paradox faced by departments of social work and social services in their development of planning strategies for community care: although SWDs hold financial and operational responsibility for the management of community care services, health care professionals generate the demand made upon those services. In other words, elderly people's use of domiciliary care services would appear, in large part, to depend upon the encouragement and actions of health service personnel.

Of the 18 carers, only three indicated that their parents' receipt of domiciliary services had been initiated by themselves, based upon their own need for support. In each of the three cases, carers indicated that they had been providing practical support for their parents prior to the delivery of domiciliary services and had made their requests for domiciliary services because of an inability to continue caring for their parents unaided:

> Really, we (*respondent and her sister*) decided to approach them to take the load off us; to help with the caring. We approached the social work department directly for daily help and I organised the day care for her (mother) with the social worker who came to the house. We were just finding it too hard before; caring for Mum and with our own families...we knew about the services and just decided to get Mum fixed up, to help us.
> carer 101

> I took on (*sic)* for another operation in my leg; I had a bad bike accident. This was three years ago and I got in contact with the social services before I went in (*to hospital*) because I needed someone for my mother. She was 87. It all looks so easy; they think 3 hours a week is a lot, but I tried to get an hour a day. My doctor even phoned the home help organiser, but she said I was coping very well...so I didn't get it.
> Carer 110

The paucity of numbers here suggests that the actions of family carers are of little consequence for the take-up of domiciliary care services by frail elderly people. The interviews with carers did not explore their reasons for not contacting the SWD personally for domiciliary support for their parent, but their failure to do so given the high levels of functional disability displayed by their elderly parents, suggests that this is an important topic for future research. For instance, analysis of carers' motives for requesting formal intervention in the form of domiciliary support would provide important information about targeting services and supporting carers: after all, until carers' attitudes and motives are better understood, knowledge concerning factors which lead to, or indeed inhibit, domiciliary service use among elderly people will remain incomplete.

Carers' Assessments of the Domiciliary Services Needed by Their Elderly Parents

Carers were asked for their opinions regarding their parents' needs for each service available under the community care programme in the SWD area. This was then compared to whether or not the 18 parents involved actually received each service, the intention obviously being to highlight any mismatch between formal assessments and carers' assessments of the elderly participants' care needs.

Table 7.5 below reveals that a high degree of unanimity existed among carers with regard to the services they considered their parents to need. **Two thirds or more carers indicated that their parents needed home helps, housing adaptations, the community alarm and day care.** Table 7.5 also reveals several notable mismatches between carers' identification of domiciliary service needs and domiciliary services received. The first concerns the community alarm which is operated by a "panic button" on a small box worn as a necklace by the elderly person in their home. Thirteen carers indicated that their parents needed such a safety provision:

> I have to work nights occasionally and I worry about her then. There's a big extension, so I always leave the telephone next to her bed at night when I'm out, but it *(community alarm)* would still be a good idea.
> Carer 121

> The community alarm would be a really good idea. She's 85 and living on her own. It would give her, and us, peace of mind.
> Carer 126

Table 7.5: Carers' Assessments of the Domiciliary Services Needed by Their Elderly Parents

N=18

SERVICE TYPE	SERVICE IS NEEDED	SERVICE IS RECEIVED
Home Help	16	16
House Adaptation	16	14
Community Alarm	13	6
Day Care	12	10
District Nurse	9	2
Transport	8	9
Respite Care	7	3
Auxiliary Nurse	7	2
Specialist Therapy	4	3
Aids e.g. wheelchair	4	3
Hospital Day Care	4	1
Meals on Wheels	2	2
Incontinence Laundry Service	2	0
Evening Care	1	0
Foster Care	0	0

Only 6 carers however indicated that their elderly parents were members of the community alarm scheme. Interestingly enough, there was some evidence of resistance to the alarm from the elderly parents themselves:

> We're really pushing for that but he won't have it. He says he doesn't want strangers coming in asking questions. But we think it's an excellent idea. Carer 141

In other cases, it was the rules of installation which prevented the elderly parents from having the alarm facility:

> They were turned down for that because there's the two of them. I ask you: my Mum can't move and my Dad's demented!
> Carer 136

A further mismatch existed between carers' identification of their parents' need for, as opposed to receipt of, the services of a district nurse. **Whereas half the carers replied that their parents needed a district nurse, only two indicated that their parents saw a district nurse.** In some cases, the district nurse had previously been attending the elderly parents but had subsequently been withdrawn for some reason:

> I think she could go in. She used to, when he had his cataracts done, she went in three times a day with his drops. But she doesn't go in now. But I think she should, just to keep an eye; just a general health check every now and then.
> Carer 114

> We were on the tuck-in (evening care) service with the district nurse, but only for about 5 weeks before the case conference. Before that, dad would get himself to bed. But he won't do it now and so they started to come in to do it because my Dad and me always ended up fighting. But when the district nurse withdrew, after the case conference, the tuck-in stopped too. They were withdrawn because social services have held the purse strings since April, I expect you know, and they wouldn't pay for the district nursing because it wasn't giving medical treatment. I think really we're caught in a fight between the NHS and social services, because changing my Dad's catheter bag and tubes, that's all done by the home help now: I've never been shown how to do it. The doctor changes the catheter every three or four months: we have to call him in to do it.
> Carer 136

A further mismatch existed between carers' identification of their parents' need for, as opposed to receipt of, auxiliary nurses. But probably the most interesting results were carers' responses regarding their parents' need for and receipt of respite care. Research consistently points towards carers' need for a break from their caregiving responsibilities (e.g., Briggs and Oliver, 1984; Warner, 1994; Kent Association for Respite Care, 1993). Respite care provides "care for the carer": it allows them to "recharge" their physical and emotional caring batteries. Of course, respite care has the added intention of prolonging the provision of family care and thus is

conceived also in terms of cost effectiveness. Of all community care services however, respite care is invariably the service which caters for the needs of carers as much as care receivers (Twigg, 1989). It is interesting to note therefore that only seven carers stated that they felt their parents should be recipients of respite care. Furthermore, some carers were equivocal about their parents' receipt of respite care. In particular, carers' comments stressed that respite care facilities had to be of a certain quality: this was necessary both to convince carers that their parents would benefit from attendance and to alleviate any guilt they felt in making use of such facilities:

> No, I wouldn't put him in there again. It must be soul destroying, because you're not allowed even to go to the toilet or to your room without two of them taking you...something to do with insurance. He's been in once. He went in on the Monday and I went to see him on the Wednesday. They were all just sitting there in a row, mouths half open, half asleep. I told him to get up and I took him outside for a walk around the garden and told him: "You make sure you do this every day". If they stay like that at his age, they just go downhill and die. Lie in bed, die in bed I always say to Dad. Afterwards, I tried to take him home, but they wouldn't let me: he had to stay in for the fortnight. But he'll no go back there again. Ever.
> Carer 114

The other major resistance to respite care concerned the reactions of elderly parents' themselves. Some carers for instance indicated that their parents regarded respite as the prelude to full-time residential care:

> She's only been in respite once, but she didn't like it because she thinks she's going to be made to stay in. Last winter she was very poorly and I asked for more home help, but they wouldn't give it to me and I was exhausted. So by the time she went into respite, it took me four days to get myself back up to date here before I could visit her and she thought I'd left her.
> Carer 110

It cannot be assumed therefore that any mismatch between carers' identification of respite care needs and respite care receipt reflects a refusal to allocate a service on the part of the formal care agency. The attitudes of both carers and care recipients were important here too:

> Aye I think she would enjoy the company. But she won't hear of it. And yet she says: "I'm sick of these four walls". It would be a different environment altogether for her. But her sisters are both in nursing homes and when you go to see them, one of them in particular I think is drugged to the eyeballs. And I think that frightens Mum: she thinks the same thing will happen to her if she goes in.
> Carer 142

Carers' Assessments on the Adequacy of Services Received by Their Parents

Remaining on the theme of care needs, carers were also asked to evaluate the amount of services their elderly parents actually received. This was done in exactly the same way as with elderly respondents: carers were asked to indicate whether their parents received "too little", " too much" or "about the right amount" of each domiciliary service actually received by their elderly parents.

This means that the numbers are very small for certain services: for instance, only one elderly parent of the 18 carers was attending hospital day care while none were receiving the incontinence laundry service. Briefly here then, of the ten carers whose parents attended day care, eight thought that the frequency of their parents' attendance was about right. Only two carers therefore thought that their parents attended too infrequently:

> It's just the day care: she could do with getting out more than once a week.
> Carer 109

> She goes twice a week; aye maybe she could do with another day. It would get her out and she likes it there.
> Carer 117

Interestingly enough however, of the three carers whose parents had used respite care facilities, (see Table 7.5 above), every one thought that their parent needed more periods of respite:

> It's not enough. I've got the two of them. It takes days to catch up with yourself after they go in. You only get a week really to relax.
> Carer 136

The major complaint among carers however concerned the inadequate amount of home help made available to their elderly parent. All but two of the carers' parents received home help support and of the 16 carers involved, eight said that their parents received too little:

> (*The SWD*) is generally good, but she should have the home help in at least another morning; she should have her twice a week. You hear of other people getting more. I'm always on to my mother that I'm going to phone, but she tells me to leave it alone. I suppose it suits my Mum. They're not home helps anymore, they're carers now. They have a blather and then I go along and do the work. To me, it's ridiculous. Do you mean to tell me they should just sit there with mess all round and just pass the time of day?
> Carer 124

Such complaints were founded upon the effects that "inadequate" levels of home help had upon carers themselves: too few hours meant that carers were having to "fill in the gaps". This evokes a familiar debate within family care research concerning the fair and effective division of care between family members and formal care agencies. Carers' complaints concerning inadequate levels of home help were founded upon the level of caring contributions they were forced to undertake as a consequence. Of course, it is important not to overstate such complaints: eight carers, the same number as those who complained, indicated that their parents received "about (the) right" amount of home help support. Nevertheless, a noticeable feature of these responses is that carers often qualified their expressions of satisfaction with caveats concerning the willingness of individual home helps to exceed their statutory duties:

> I couldn't cope without her (*home help).* She's a good support to me; she's very good. And she continues to try to do the cleaning even though she's not supposed to. She really is great.
> Carer 136

There was some evidence to suggest therefore that when carers were satisfied with the levels of home help their parents received, this was contingent upon the personalities and willingness of the home helps themselves to provide a service above and beyond formal requirements.

Carers' Contact with Domiciliary Care Workers and Managers

As the discussion about community care policy and practice revealed at the beginning of this chapter, the support of family carers is a well promulgated feature of contemporary community care arrangements, (e.g., DoH 1990, 1992 and 1993). Integral to much of the official guidance issued since 1990 is the inclusion of carers' needs in assessment procedures and their practical support in service delivery. The final exploration of data here therefore concerns the types and levels of contact carers have with the organisers and deliverers of domiciliary care services. Although this research is not an exercise in programme evaluation, this aspect of care management is of obvious significance to the next chapter which explores the ways in which family and formal care interact at the site of care delivery.

Specifically, carers were asked:

> And what type of contact do you have with the people who organise and deliver the services your mother/father receives?

If necessary, carers were prompted in order to ascertain the identity of the person(s) they had contact with, the nature of that contact and the regularity of that contact. The results reveal that the great majority of carers had minimal, if any, contact with the organisers of domiciliary services: they did not know the identity of their parents' social workers nor were they in contact with the area home help organiser:

> There's no contact. I mean, I've got a name and a contact number, but there's no contact.
> Carer 101

> None at all. My wife saw the home help once in a while if she was round there at the same time as the home help was there. But no, we've never spoken to anyone about Mum.
> Carer 144

Such comments emphasise that carers had never been consulted about, let alone included in, any assessment procedure when domiciliary services were being organised for their parents . In other words, carers' "needs" were not incorporated into care assessment procedures, nor had their preferences been canvassed for care management purposes. Indeed, **only four of the 18 carers said that they had ever been in contact with the home help organiser and only five carers indicated they had ever been in contact with their parents' social workers.** More disappointing still, even among these few cases, carers indicated that their contact with the social workers or home help organisers was isolated and ad hoc rather than regular or systematic. This meant that there was very little ongoing dialogue between the organisers of domiciliary care and the adult children carers:

> As far as the bosses are concerned, I get a phone call once a year from the home help organiser to see if I'll do Christmas and New Year (*look after father during holidays*). So this year, I'm going to find out who's on duty and get them to do his meals.
> Carer 114

> If anything goes wrong, I have to run round and find out for myself. We had thesocial worker a year and a half ago, and the home help organiser. But I've no seen him or her since. The social worker told me we could get this, that and the other, but then the home help organiser told me we could only get half an hour every morning: something to do with their budget she said. So you don't know what to think even when you do see them.
> Carer 129

In fact, only one carer stated that he enjoyed regular contact and support from a domiciliary care manager:

> They give me a ring regularly to see how things are going because they know I've also been having problems with my daughter...So I talk to the social worker a lot. I'm seeing her next week. She's not my daughter's social worker she's my Mum's, but she knows the situation.
> Carer 110

The views, circumstances and preferences of carers seemingly played virtually no part in the establishment and ongoing management of domiciliary services. Rather, the results revealed that carers' contact with individual domiciliary service providers was concentrated at the delivery end of the spectrum: it was the

individual home helps that carers were in contact with. Overall, 11 of the 18 carers said that they saw their parents' home help:

> Well I speak to the home help all the time because she's there when I go at lunchtimes...In fact it was her *(home help) that told the organiser that Dad was needing much more and that's how he got one (a home help)* for his breakfast. So now, she makes his breakfast for him, does his fire (that's unofficial because she's not supposed to), and then goes. She keeps his house as if it were her own father. Mind you, she's just lost her own father so she pays more attention to Dad. And when she comes back, she makes him his lunch and cleans up. And then she takes his washing away with her...and she's not supposed to do that either.
> Carer 114

> No there's no contact really. Just with the home help if we're along on a Friday when she comes, I'll speak to her then. The annoying part is when *(home help's)* on holiday, she no gets anything or anyone.
> Carer 124

It is important to note that these comments reveal that the basis of carers' contact with their parents' home helps was more coincidental than systematic: carers saw their parents' home helps when they went to see their parents for themselves. Thus even when regular contact existed between family carers and home helps, its foundations were unlikely to promote any effective and long-standing formal care-family care co-ordination.

While family-formal interactions are the focus of the next chapter, the conclusion drawn here is that family carers and domiciliary support operated independently of each other. Very few carers were in contact with any domiciliary care managers, although the majority did get to see their parents' home helps fairly frequently. Such an operational model is very different from the template promulgated in the 1990 legislation. The descriptions carers gave about their contact with those people responsible for organising and delivering domiciliary care in the SWD revealed that their needs as carers were not assessed, their preferences for service delivery not ascertained and their individual circumstances rarely taken into consideration. At this stage in the analysis therefore, scepticism expressed by community care pundits regarding the probability that carers' needs and preferences will be

incorporated into the care management process as a result of the 1990 National Health Service and Community Care Act and subsequent guidance seem well-founded.

Summary and Conclusions

The aim of this chapter has been to allow elderly users of domiciliary services and their filial carers to speak about their experiences of domiciliary services and to place those experiences within a policy context. It should be recalled here therefore that my fieldwork was conducted at an important stage of the community care planning and arrangements set out in the 1990 legislation: legislation which had been published but which had been subject to delays in implementation. From a policy perspective therefore, many of the criticisms voiced by users and their carers may by now have been outstripped by events, most particularly those proposals which called for the introduction of care management mechanisms. Furthermore, the soon to be implemented Carers Act may also obviate, or at least reduce, some of the carers' criticisms about service planning and lack of service user involvement. Policy caveats aside however, the data presented in this chapter have raised a host of issues.

The analysis first looked towards the referral process and how elderly participants first came into contact with domiciliary services. The results emphasised the pivotal position occupied by health care professionals here. Indeed, in only nine cases had carers been the referral agents. Despite a policy of open access therefore, elderly participants' accounts revealed that access to domiciliary care was heavily controlled by professional groups.

The actual receipt of domiciliary services was largely synonymous with home help provision. A key result concerned service rationing; over a third of elderly participants who received an allocation of home help complained that it was too little and over two thirds of all elderly participants stated that they needed services or help from the local authority in addition to those they already received. When

juxtaposed with participants' assessment of the difficulties they experienced in undertaking certain tasks, the data highlighted the continuing occurrence of significant care gaps.

Part of elderly participants' unmet need resulted from a restrictive code of practice that delimited the home help job description, but there also was an apparent absence of any regular or systematic reassessment of users' or carers' care needs. Both groups, although carers in particular, had very little contact with community care managers: their experiences of service allocation decisions were pegged at the level of the home help organiser and individual home helps (and even here contact was predominantly incidental rather than planned). The issue of cuts in domiciliary services was also raised by both groups and part of their criticisms concerned the ways in which service reductions were managed. There was often no prior warning about reductions in services nor explanation provided. Furthermore, there was no evidence to suggest that service reductions were any way related to a participant's or carer's needs.

The predominant relationship between service users, carers and domiciliary service management was completely unco-ordinated. Neither elderly participants nor their carers showed any awareness, or experience, of formal assessment procedures: elderly participants simply started to receive home help support because "their doctor had a word" or because they had recently been in hospital and "it had all been organised from there". Both groups were also at a loss to explain why services were pegged at the levels they were and demonstrated that any action they took in opposition to managerial decisions often resulted from their informal discussions with individual home helps or day care staff. "Service user involvement", whether limited to the participation of service users in decisions which personally affected them or extended to involvement in decisions which affect whole categories of service users, was most certainly conspicuous by its absence.

Despite their criticisms concerning operational management practices however, many service users and carers revealed a sincere gratitude for the domiciliary care received and in particular for the efforts of individual domiciliary carers. In other words, it was the private face of domiciliary services that elderly participants and their adult children appreciated the most; a sympathetic private face which was belied by public policy and practice.

8

THE RELATIONSHIP BETWEEN FAMILY CARE AND DOMICILIARY SERVICES

> ... knowledge concerning the relationship of services to informal carers is still deficient. There are three broad areas in which this is the case. The first concerns policy and practice; the second the levels and patterns of provision for carers; and the last the effectiveness of services.
> Twigg, Atkin and Perring, 1990 p67

Introduction

Many studies document the provision of family care to, and the use of formal community care services by, elderly people. The assumption which underlies both agendas is that the presence of family members and their availability for care provision are salient factors in decisions which determine the allocation of community care services. In other words, family care is the fulcrum of community care, (Twigg, 1993 p141), meaning that community care represents the systematic mechanism through which family and domiciliary care may be linked.

Linking family care with domiciliary care however is complicated by at least three factors. First, family and formal care operate according to very different principles and practices (Abrams, 1978). Criteria regarding eligibility and budgetary limits control the delivery of domiciliary services, while the provision of family care is based upon the relationship between normative familial obligations, emotional bonds between kin and practicality (Qureshi, 1990 p60). Second, each system of care has divergent internal relationships and interests. Formal care is understood primarily in terms of tasks performed by specified persons working within a system of statutory responsibility in response to formally assessed needs (Challis and Davies, 1986). Family care on the other hand is rooted in affect, kinship and

biography. Of course family care also results from social norms (Finch and Mason, 1992), but it is framed in terms of the relationship between the giver and receiver of care in a way in which formal care is not. In other words, while both formal care and family care can be conceptualised in terms of tasks performed and measured in terms of service levels and categories of tasks provided, family care has the added dimensions of normative obligations, familial duty and affective support (Graham, 1983; Dalley, 1988). Third, the levels of support available from the two sectors are markedly uneven and are, of course, skewed towards the primary contribution of family care.

Such differences account for the way in which the two sources of care have been separated in the caregiving literature. Indeed, such separation has resulted in "an enormously fruitful outcome" (Ungerson, 1995 p32), in terms of emphasising the primacy of family care, its feminine specificity, origins and effects. Recently however, the distinctions between formal and family care have come under review (e.g., Graham, 1991; Thomas, 1993; Ungerson 1990), and there has been a growing realisation that the two need to be addressed in frameworks capable of amplifying upon conceptual, ideological and material similarities as well as differences (Ungerson, 1995).

At the material level, there remains a dearth of data describing how family and formal care concentrate, combine, or indeed confuse their respective efforts at the site of care delivery:

> What is lacking is a systematic investigation of how services provided through a bureaucracy intervene in family caregiving.
> Quadagno et al 1980, p117

This lack of information provides a major theme for this study: examination of the family system of care for aged parents as a context for formal intervention and linking with welfare.

The aim of this chapter is to describe the relationship between formal and family care that occurs at the site of care delivery as experienced and described by elderly care receivers and their adult children carers. Specifically, this chapter explores two aspects of the family/formal interface: elderly care receivers' attitudes towards the acceptability and quality of domiciliary services; and care receivers' and carers' descriptions of the impact of formal services upon family care. The third aspect of the family/formal interface, the meanings that care receivers and carers attach to the two sources of care, is an enormous area and is examined separately in the next chapter.

As far as the author is aware, assessment of the family care/formal care interface from the perspective of the care receiver represents uncharted territory in British family caregiving research. By way of necessary preamble therefore, the chapter begins with a critique of the literature which describes the boundaries and contours of the family and formal care interface.

Defining the Family Care-Formal Care Interface

The paucity of research which addresses the combined efforts of family and formal care and the ways in which they "interweave" (Bayley, 1973), may, in part, be explained by the observation that the underlying relationship between social care agencies and family carers is ambiguous. Family carers occupy "an uncertain and fragmented" position within the social care system (Twigg et. al., 1990, p67), and part of the ambiguity results from the variety of roles into which carers are cast by social care agencies: clients, co-workers, and/or a free resource to be exploited to the fullest extent (ibid). The effects of such multiple casting are of obvious significance to carers themselves: they are likely to affect the levels of formal services deemed necessary, flexibility in the delivery of any services and even the strategic direction of the individual community care plan.

The contours of the family care/formal care interface are complicated further by the ways in which social care agencies operate. They are regarded as inflexible in their response to the individual needs of carers and paternalistic in their approach to carers and care receivers alike (Qureshi, 1990; Hoggett, 1991; Walker, 1993). Consequently, carers have been traditionally excluded from the decision-making process that governs the delivery of formal care services. Indeed, community care services have rarely been developed with the support of carers as a primary objective and any benefits carers derive from the delivery of formal services are often attributed to chance:

> Consequently, carers' needs, or the way in which they might best be helped, are rarely taken account of in any systematic way. Despite the proliferation of accounts of services intended to support carers, instances of planned and monitored intervention are still comparatively scarce.
> Parker, 1990 p95.

This means also that any relationship between service users (including carers), and community care managers is characterised by "unequal power relationships" (Lindow and Morris, 1995 p2), and a key recent research initiative has been the examination and analysis of service user "involvement" or "empowerment"[1] (e.g. Croft and Beresford, 1990; Stevenson and Parsloe, 1993; Ellis, 1993; Morris, 1994).

Despite attendant ambiguity and inequality, however, the relationship between formal care and family care is necessarily symbiotic. In particular, recognition that family care and its encouragement is the fulcrum of community care policy and an increasing awareness of the costs and burdens borne by carers help to focus attention on the impact of formal services upon family carers. It also concentrates attention upon the usefulness or otherwise of public services in maintaining and improving family care:

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[1] Olive Stevenson and Phyllida Parsloe (1993) provide a cogent critique of official initiatives designed to increase service user "involvement" and reject the predominant consumerist model by which such involvement is effected. Instead, they call for a redistribution of power between users and providers and focus on the need for users and carers to be "empowered".

> Carers cannot be regarded simply as a kind of background resource - a social phenomenon whose nature agencies need to understand and which is best analysed as part of the informal sector in general; rather they are a moral category towards which agencies themselves have obligations, however difficult they may find it to define those exactly.
> Twigg et al, 1990 p5

The public policy significance of the family/formal alliance is heightened by the increased longevity of elderly people, and the burgeoning of "caring careers" (Brody, 1990). Integral to the notion of a caring career is the effect of an elderly relative's increasing care needs over time upon the role attributed by formal agencies to family carers. The promulgation of charters which specify users' and carers' needs and rights also focuses attention upon the family care/formal care interface, (see Bornat, 1993 p262-275). The rhetoric of such documents is composed in terms of self-determination and the rights of service users and their family carers: their intent concerns the incorporation of those rights into public policy and practice. Generally, though, consideration of how carers' needs and rights may be integrated into the service delivery system is conspicuous by its absence in both policy statements and long term care research.

A notable exception is provided by Julia Twigg who assessed the potential benefits offered to carers by evaluation, consumerism, case management, performance indicators, rights and targets. Twigg concluded that case management offered carers the best way forward because it provides an opportunity to "negotiate" with service managers about the services required. Twigg's optimism about case management was tempered by recognition of the effects of resource constraints in community care planning and the practical limits this creates for care managers; nevertheless, she highlights case management because it is the mechanism which best highlights the needs and opinions of carers (Twigg, 1993, p167-8).

Emily Abel also places carers' needs at the centre of any interaction framework and starts with the principle that carers' needs should form the basis of formal intervention (Abel, 1989). Although her research concentrates upon the support available to carers as provided by family or friends, she identifies the gamut of

formal supports that carers require. Also important, she treats carers' needs in an holistic manner set within the context of the caring unit; a unit that includes the needs of the recipient of care as well as the provider of care and which rejects the separation of carer from care receiver. Abel's research highlights the variety of support required by family carers including instrumental assistance, emotional sustenance, companionship and approval. For formal services to intervene effectively in family care therefore, the implication is that they also need to embrace multiple aims and outcome measures which correspond to the variety of identified carer needs.

With regards to the support that formal services provide carers, the evidence available paints a confused picture because disabled people with similar needs receive very different levels and types of formal services (Arber et al., 1988; Qureshi and Walker, 1989). Although this may reflect an inherent bias of formal services towards certain household and family types (Green, 1988; Ginn and Arber, 1992), it also suggests that disabled people and their family carers respond to the demands of caring in idiosyncratic fashion; that they define their caregiving situations differently and make different use, if any, of the variety of services available (Ginn and Arber, 1992 p117-8). In other words, families respond differently to different types of dependency (Moore, 1987); hold different views on the normative responsibilities of different family members (Brubaker and Brubaker, 1989, p248); and develop their own caring strategies (Matthews, 1989).

As a result of these divergent concerns, the family care-formal care interface is perhaps best defined in terms of a "triadic" relationship between care receiver, family carer and social care agency. Research, however, has tended to focus on either the performance of social care agencies, (e.g., Challis and Davies, 1985 and 1986), or the provision and burdens of family caregiving (e.g., Baldwin, 1985; Braithwaite, 1990; Gilhooly, 1984; Nissel, 1984). There is little systematic investigation of how formal services intervene in family caregiving, a lack of knowledge concerning the impact of service provision upon caregiver burden, and

also very little information on care receivers' preferences for, and experiences of, domiciliary care.

Conceptualising the Family Care-Formal Care Interface: Frameworks of Analysis

Paradoxically, the dearth of descriptive data concerning the family care/formal care interface is counterbalanced by a cornucopia of conceptual "linkage frameworks". These include: conflict, competition, co-optation, coexistence and collaboration (Froland, 1980 p576-579); substitution and specialisation (Greene, 1983); shared-care (Moroney, 1976); supplementation (Spivak, 1984); complementarity (Sussman, 1977; Litwak, 1985); neglect, confusion and colonisation (Snaith, 1989); and independence (Edelman and Hughes, 1990). The discussion here concentrates upon the work of three authors whose linkage frameworks cover the themes of most concern to theorists: Robert Moroney, Eugene Litwak and Philip Abrams.

Robert Moroney advocates "shared care" as the optimal interaction mechanism between domiciliary services and family care. This involves a partnership between family and formal care and rejects the notion that the two systems operate in contrary, or contradictory, ways. Moroney asserts that the welfare state is predicated upon certain assumptions concerning the normative responsibilities of the family and its members and the identification of specific situations which determine the suitability for the state to participate in, or to assume responsibility for, the direct provision of social care (Moroney, 1976 p9). He argues that the development of the welfare state has been accompanied by an increase in demand for social welfare services and thus the notion that state provision actively dissuades families from assuming their responsibilities to care for elderly kin is one of his major concerns (Moroney, 1983 p189-90); a concern which also, of course, resounds throughout official documents (e.g., DHSS, 1981 para 1.8; Griffiths, 1988).

Based upon the observation that the majority of people require no support other than that which they marshall from their families or from private means, Moroney argues that the proper role of the state is one of marginal provision for a minority of people (Moroney, 1976 p95-7). He also argues however that when state intervention in the form of public services is necessary, carers and those they care for should be presented with real choices about the organisation of formal services. Moroney asserts that the role of formal services is therefore both substitution for, and support of, family carers: a scenario in which care is ultimately "shared" (ibid., p96). Indeed, Moroney's position is reminiscent of the Seebohm Committee whose influential report stressed the "enabling" function of the social welfare system, (Seebohm, 1968):

> The primary objective of the personal social services we can best describe as strengthening the capacity of the family to care for its members and to supply, as it were, the family's place where necessary: that is to provide as far as may be social support, or if necessary a home for people who cannot look after themselves or be adequately looked after in their family.
> Hansard, 26 February 1970 column 1407

Moroney concludes that whilst the government attributes primary responsibility for care to the family, it has a significant role to play in situations where family care is ineffective or unforthcoming. "Shared care", a "care partnership" or "interweaving" are all but different ways to describe this interaction between families and the state: a supplementation of family care by formal care (e.g., Land and Parker, 1978; Parker, 1981; Bayley, 1982; Walker, 1982). Once operational, supplementation involves a sharing of overall tasks between formal and family care; but such sharing is inherently predicated upon the inability of family carers to maintain their caring contributions (Tennstedt et. al., 1989).

An important exposition of the shared care thesis is found in the 1988 Green Paper authored by Sir Roy Griffiths, the architect of contemporary community care arrangements and stresses that the primary role of publicly provided services is to support informal carers (Griffiths, 1988 para 3.2).

Indeed, Griffiths regarded family carers as the focus around whom formal services should be organised and delivered (Wistow and Henwood, 1991, p91). Although conceptually accessible, the major failings of the shared care polemic revolve around problems of practice; a shortcoming conceded by Moroney himself:

> Serious problems and disagreements emerge however, when attempts are made to translate the concept of shared care responsibility into specific social policies and programmes, for then it becomes appropriate to define what functions are appropriate to each.
> Moroney, 1976, p117.

Fundamentally, the inherent incompatibility of formal and family care lies at the root of the problem here: how can formal services substitute for family care when the two sectors have contradictory structures, goals, and ways of working? Such criticism is a prime consideration of Eugene Litwak:

> How, then, is one to explain the paradox of two kinds of groups with contradictory structures, achieving their goals by working closely together?
> Litwak 1985 p253.

Litwak argues that the analysis of the relationship between formal and family care is conceptualised by four constructs: supplementation, complementarity, substitution and independence (Litwak and Meyer, 1966; Litwak, 1985). This framework has been used as the basis for other research into formal care/family care relations (e.g., Noelker and Bass, 1989; Berry et al., 1991), and lends itself to simple summary. "Supplementation" involves formal care providing assistance with tasks also undertaken by family carers. "Complementarity" occurs when formal services and family carers undertake different but mutually beneficial tasks. "Substitution" involves a replacement of family care by formal care and "independence" is when family carers receive no help whatsoever from formal services.

In particular, Litwak insists upon the inherent complementarity between family and formal care: the family and the state manage different but complementary aspects of the provision of support to elderly people. He contends that formal

services are best equipped to fulfil assessed instrumental and specialist needs, while family care is best suited to unpredictable, personal and expressive forms of support (Litwak, 1965). By way of rationale, Litwak theorises about matching group structure with task structure and demonstrates that primary groups (i.e., families), as well as formal organisations are best suited to managing tasks that match their structure:

> The fact that formal organisations and primary groups have such radically different structures means that they can manage different tasks.
> Litwak, 1985, p262.

Litwak maintains that care receivers require assistance from both sources of care in order to effect "optimal goal achievement": families and formal services have different abilities which, only when combined, can meet an individual's total care needs. This combination however involves both sources of care having to "mute the conflict sufficiently so that they can work alongside each other, despite their differences." (Litwak, 1985, p253).

Of course, the logical outcome of Litwak's complementarity thesis is that formal care can never fully substitute for family care. Formal care may, however, assume responsibility for certain aspects of family care, in particular those tasks which lend themselves to routinisation and/or specialisation (Litwak, 1985, p256; Chappell, 1985; Edelman and Hughes, 1990). In other words, the state and the family "share care", but via a strategy of specificity, (complementarity), as opposed to supplementation, (as in the Moroney text).

Independence in the Litwak framework occurs when the receipt of family care and formal care is uncorrelated. Evidence quoted in support of this independence asserts that levels of disability and perceived need are less important criteria in decisions which govern the allocation of formal services than gender, household type and identity of family carer (Chappell and Blandford, 1991). For instance: elderly people living alone are six times more likely to receive a home help, and eight times more likely to receive meals-on-wheels than those living with other relatives (Parker, 1985 p70); elderly people being cared for by married adult

children are less likely to receive domiciliary services than those being cared for by single adult children (Hunt, 1978; Nissel and Bonnerjea, 1982); male carers receive a greater range of services than women carers, regardless of dependency levels (Bebbington and Harris, 1983); and the support provided by formal agencies is very limited amongst the elderly population at large, and where it is provided tends to be medical rather than instrumental (Evandrou et al., 1986 p161).

These findings suggest a hierarchy of service provision fundamentally independent of the needs of elderly people and their families (Parker, 1985 p70); a hierarchy which primarily reflects normative assumptions about the responsibility of different family members to carry out certain tasks for their frail kin (Twigg et. al., 1990; Parker, 1990). A potential consequence of such independence is the occurrence of "care gaps" (such as those uncovered earlier in chapter four), in which the needs of elderly people fail to be met either by the family or formal services (Qureshi and Walker, 1989, p260-1).

Common to both the Moroney and Litwak texts is a preoccupation with the notion that formal care substitutes for family care: an interaction which evokes simultaneous concern and encouragement. Concern originates from the right of the political spectrum and is founded upon the inherent desirability of community care services and the logic that supply creates its own demand (see Abel, 1990, pp35-37). Because domestic and personal care is purchased by people without functional impairment and is a socially desirable service, there is the concern that any proliferation of community care services will serve to stimulate underlying demand. This increased demand is accompanied by an abrogation of familial duty, which, in turn, encourages formal care to substitute for family care.

With the exception of a few isolated studies, (e.g., Greene, 1983; Spivak, 1984; Litwin and Auslander, 1988), empirical data refute the substitution hypothesis. Furthermore, research fails to demonstrate that the availability of home care services provides any catalyst to increase underlying demand (Brody 1990, p41). Indeed, family caregiving research is unequivocal in its assertion that families

provide the vast majority of care received by functionally disabled people, (Henwood and Wicks, 1984; Green, 1988; Qureshi and Walker, 1989; Walker, 1981). In reality, family carers often make little use of formal domiciliary services, (Evandrou et. al., 1986; Brubaker, 1989 p245; Brody, 1990), and studies reveal that the allocation of formal services is biased towards those individuals with no access to family care (Twigg et. al., 1990). Furthermore, even when high levels of family care are being provided, surveys illustrate that the intervention of formal services serves to prolong, rather than replace, family care (e.g., Green, 1988). Despite such "grounded" data, however, the political fear that formal services encourage a familial retreat from care provision persists and provides a rationale for any limitation of public provision.

By way of direct contrast, the argument that formal services should be designed in order to substitute for family care derives from the feminist critique of community care; a critique founded upon the knowledge that community care in practice refers to unpaid work performed by wives and daughters for their disabled kin (e.g., Land, 1978; Finch and Groves, 1983; Baldwin and Twigg, 1991). The feminist clarion resounds with the need to reform community care services so that women carers are provided with respite from their family caregiving work and amelioration of their caregiving burden (e.g. Finch, 1984; Dalley, 1988). For purposes of women's equality and distributive justice within the family, the feminist approach to the family care-formal care interface stresses the desirability of formal services substituting for family care.

Two problems confound a "feminist restructuring" of community care services: the lack of interchangeability between formal and family care; and a conflict of interest between family carers and care receivers. First, there is a real question mark over whether an hour of home help equates either to an hour of family care or to an hour of respite for the family carer, (Abel, 1987 p36; Berry et. al., 1991). There is also scepticism as to whether the delivery of formal services results in a lessening of the burden of care for family carers. Equally difficult to resolve is the dilemma posed by the perception that care receivers prefer family care to formal

care; a preference which results from qualitative differences in the meanings attached to each form of support (Ginn and Arber, 1992). Fundamentally, family care differs from formal care because of affectual and kinship origins: origins which are necessarily absent in discussions concerning the allocation and delivery of formal services. Any substitution of family care by formal care therefore may result in a decline in the quality of care as perceived by care receivers, and thus involve a conflict of interest between family carers and their frail kin.

In reality, evidence suggests that over time volunteers and paid workers increasingly assume the affectual characteristics generally associated with family care, (Archbold, 1983; Seyd et. al., 1983). Furthermore, evidence concerning elder abuse forces the conclusion that families may deliver the very worst, as well as the very best, care (Whittaker, 1995). Indeed, there is data which suggests that family carers themselves believe that "outsiders" deliver better and more appropriate care because of the highly-charged atmosphere that may exist within the caring relationship, (Abel, 1990, p38).

Thus the qualitative distinction made between formal care and family care may be exaggerated:

> It often is impossible to differentiate neatly between the activities of formal service providers and those of family members. Some paid helpers do form emotional attachments to their elderly disabled clients and cater to their idiosyncratic needs and individual personalities. Conversely, some family members furnish care from a sense of obligation as well as affection
> Abel, 1990, p37.

Echoes of the material and affectual similarities between family care and formal care reverberate in the British caregiving literature, (e.g., Ungerson, 1995). Nevertheless, any perceived conflict of interest between carers and care receivers presents the feminist demand for substitution of family care by formal care with a real dilemma. Whose interests should prevail? Those of (women) carers or (women) care receivers? (Morris, 1992). And if neither set of interests should necessarily take precedence, what comprises an acceptable compromise for each group?

The final framework of the family/formal interface examined here is provided by Philip Abrams' research into neighbourhood care. Abrams first makes the distinction between "traditional" and "modern" types of informal care (Abrams, 1984 p414-16): a distinction based upon the variability of social relationships underlying the giving and receiving of such care. The "traditional" form of informal care is created and defined by societal norms and obligations (such as those that exist between aged parents and their adult children). "Modern" informal care however is reliant upon choice rather than constraint and results from friendship rather than duty. Abrams argues that the two forms of informal care evoke four possible interactions with statutory agencies: unfortunately he fails to relate the two formats of informal care to each interaction in any specific way.

Caveat aside, Abrams first identifies *colonisation*; an interaction whereby social care agencies directly invade or dominate informal care arrangements. Specifically, colonisation adopts one of three formats: domination, appropriation and incorporation, (Abrams 1984 p421). "Domination" occurs when statutory services are seen to define the duties of informal carers and impose upon them responsibilities which suit their own bureaucratic needs. "Appropriation" on the other hand involves a formalisation by statutory agencies of activities undertaken by informal carers and uses a strategy whereby central figures in the informal sphere are incorporated into the formal sector as gatekeepers. To elucidate here, Abrams provides the example of a Social Services Department attempting to assimilate a Good Neighbours scheme into the administrative remit of domiciliary care (ibid., p423). "Incorporation", however, attempts to integrate formal and informal systems of care via the application of informal care mechanisms and procedures to the administration of statutory services. That is, statutory services respond to the organisation of informal care and attempt to "draw the informal sector into an over-all system of care with the least possible disturbance of its existing internal relationships." (ibid).

Secondly, Abrams identifies *conflict* as a feature of relations between statutory agencies and informal care. Conflict is attributed to the politicisation of informal

carers who realise that the goals and methods of delivery of statutory services are necessarily contrary to their own. They recognise that formal services are not orientated to the alleviation of their caregiving burden and as a consequence become increasingly dissatisfied with formal services. Their relations with service managers and service workers gradually adopt an adversarial nature, and their needs as carers are increasingly presented as political demands (ibid., p425).

Thirdly, Abrams describes *integration*: an interaction whereby informal care is strengthened in such a way that it negotiates with statutory services on an equal footing (ibid., p426). In effect, the values, norms and relationships of informal care are brought to bear in the organisation of statutory services and adopted by those services as policy goals. Integration therefore involves a fusing of goals and methods between statutory agencies and informal carers.

Finally, Abrams argues that *confusion* is the most common form of interaction between statutory agencies and informal care. Simply stated, neither informal carers nor statutory agencies have found effective methods by which their contrary aims and delivery mechanisms can be jointly harnessed at the site of care delivery. As a result, the needs of the disabled person are inadequately addressed and care is delivered in an uncoordinated way whereby neither system of support is effectively deployed. A potential outcome of such confusion is the occurrence of "care gaps" whereby the needs of the disabled person are not fully met (see Qureshi and Walker, 1989, p259-61).

The three linkage frameworks have been presented in a simplified fashion, but an important common facet is their inherent recognition of the limits to family care. For community care services to be effective in their aim to support family care therefore, such limits must be taken into consideration. Dependency type and level, a carer's familial and socio-economic circumstances and the quality of the relationship between the carer and care receiver all impinge upon the experiences of giving and receiving care and affect the need for intervention by formal services. Once formal services are secured, the impact of that intervention upon

family care is likely to be affected by service users' and carers' attitudes regarding the acceptability of using the formal service system and the quality and scope of services being delivered.

These latter factors are overlooked by each of the frameworks presented above: an omission which may be partly explained by the lack of empirical research in this area. For this reason, the description of the study data below begins with an overview of elderly participants' attitudes towards the quality and use of formal community care services.

The Study Data

The examination of elderly care receivers' attitudes towards their receipt of domiciliary services was undertaken because they may have affected patterns of service use. For instance, any reluctance on the part of care receivers to accept formal services may have encouraged an adversarial type of relationship with social care agencies and encouraged the allocation of inappropriate levels and types of formal services. Attitudes towards the receipt of domiciliary services fell into two groups: attitudes regarding the acceptability of using formal services; and attitudes regarding the quality of services. The questions posed were based upon the constructs examined in The Community Service Attitude Inventory developed by researchers at Michigan State University, (see: Collins et. al., 1991), and focus on five aspects of domiciliary services usage: concern for the opinions of others about using services; confidence in the formal services system; preference for informal care over formal care; promotion of informal carer independence; and attitudes towards government responsibility for the provision of community based services.

Specifically, care receivers were asked to indicate whether or not they agreed with the statements listed below. These are grouped into their respective components but during the interviews they were scattered in order to maximise the reliability of

responses. Furthermore, the reversal of certain items was conducted in order to check response validity.

Concern for the Opinion of Others

1. People outside my family think less of me because I use services from the Social Work Department (SWD).
2. My family supports my use of services from the SWD.
3. My family thinks less of me because I use services from the SWD.
4. My family are unhappy about my using services from the SWD.
5. My family feels good about using services from the SWD to help take care of me.

Confidence in the Formal Services System

1. People employed by the SWD can take as good care of me as my family.
2. People from the SWD follow my directions in taking care of me.
3. I am fearful of having people from the SWD looking after me.
4. The SWD might have better ideas about caring for me than my family.
5. It's hard to trust anyone from the SWD to take care of me.
6. People from the SWD are better at caring for me than my family.

Preference for Informal Care

1. I would rather use services from the SWD than ask for help from my family.
2. I would rather ask my family for help than ask the SWD.
3. I would rather ask for help from the SWD than ask for help from friends.
4. I would rather ask my friends for help than ask for help from the SWD.

Promotion of Caregiver Independence

1. My family is proud to be able to care for me with little help from the SWD.
2. I believe that families should care for their own and not ask for outside help.
3. My family thinks they should care for me without outside help.

Acceptance of Domiciliary Services

1. It is not the government's responsibility to take care of me.
2. I would use more services from the SWD if they were available.
3. The government should support more social services to help families care for elderly relatives.

In presenting the results, the reader should note that the numbering of items in the tables below corresponds to that given above. Instead of repeating each question verbatim, summaries are provided in the Tables themselves. Furthermore, the tables reflect only the "agree" responses.

The first component examined elderly participants' attitudes towards the opinions of other people concerning their use of domiciliary services. The data presented in table 8.1 reveal that elderly respondents attributed negligible social stigma to their receipt of community care services: **only 5 per cent of respondents answered that people outside their family thought less of them because they were domiciliary service users**. Furthermore, respondents cited widespread familial support for their use of such services, although it is notable that female participants' stated that their families were particularly supportive of their service use (items 2 and 5 in table 8.1). Of course, the participants were all service users and thus the issue of non-take up and the attitudes of family carers in determining that non-take up did not apply; nevertheless, these results strengthen the argument that any bias in the allocation of domiciliary services results from the formal assessment criteria applied rather than service take-up problems.

Table 8.1: Concern for the Opinions of Others with Regard to Using Community Care Services

Statement:	Men n= 18 (%)	Women n=39 (%)	Total N=57 (%)
1. Others critical about service use	-	3	3 (5)
2. Family support service use	12 (67)	32 (82)	44 (77)
3. Family critical about service use	-	1	1 (2)
4. Family unhappy about service use	-	2	2 (4)
5. Family approve of service use	9 (50)	28 (72)	37 (65)

Table 8.2 below illustrates that over half the elderly participants **(54%) agreed that carers employed by the SWD provided an equivalent quality of care to family members.**, (item 1 below). And while this result contradicts the qualitative superiority used to distinguish family care from formal care, it also places a question mark over the impact of service receipt longevity and services users' perceptions of qualitative equivalence with family care. Specifically on this matter, 64 per cent of respondents who had received formal services for five years or more attributed qualitative equivalence between family and formal care. This compared to 52 per cent of those in receipt of services for under five years. Thus the evidence here suggests that the qualitative distinction care receivers made between family and formal care diminished, but only slightly, with length of service receipt.

By way of contrast, **service users rarely considered formal carers to be better than family carers:** only 21 per cent of respondents agreed with the statement that people employed by the SWD took better care of them than their family carers (item 6 in table 8.2 below). This result strengthens the argument regarding services users' perceptions of qualitative equivalence or similarity between formal and family care as opposed to the inherent superiority of one system over the other. Interestingly, however, 40 per cent of elderly participants agreed that SWD employees might have better ideas about the care they required than their family members. Whether elderly people thought that formal service workers were better informed than family carers about the variety of services available or whether it reflected some other consideration can only be guessed at here. Nevertheless, it confirms the overall impression made by Table 8.2: elderly service users had a high degree of confidence in the domiciliary services they used.

Table 8.2: Confidence in Community Care Services

Statement	Men n=18 (%)	Women n=39 (%)	Total N=57 (%)
1. SWD care is as good as fam. care	10 (56)	21 (54)	31 (54)
2. SWD carers follow directions	14 (78)	33 (85)	47 (82)
3. Fearful of SWD carers	2 (11)	7 (18)	9 (16)
4. SWD have better ideas about care needed	8 (44)	15 (38)	23 (40)
5. Hard to trust SWD carers	1	7 (18)	8 (14)
6. SWD carers better than family carers	4 (22)	8 (20)	12 (21)

Table 8.3 reveals highly equivocal results with regards to participants' preferences for family care over formal care. **Half of the male respondents, and just under half of the female respondents, stated that they preferred to ask for help from the SWD than from their families.** Of particular note however is an apparent gender dichotomy in responses concerning the question on reversal: only 17 per cent of men, compared with 51 per cent of women, stated they preferred family care to formal care.

This suggests that the male participants were particularly reluctant to call upon their families for practical support. More generally, however, it reinforces the observation made in chapter three that elderly people are generally disinclined to ask for help from their families. Table 8.3 also examines the significance of Abrams' "modern" informal care system and reveals the low significance elderly care receivers attached to friends in their preferences for carers. For these elderly people in particular, therefore, any faith in the potential offered by "modern" systems of informal care would appear to be misplaced.

Table 8.3: Preference for Informal Care Over Formal Services

Statement	Men n=18 (%)	Women n=39 (%)	Total N=57 (%)
1. Prefer SWD services to family help	9 (50)	18 (46)	27 (47)
2. Rather ask family for help than go to SWD	3 (17)	20 (51)	23 (40)
3. Prefer SWD services to help from friends	12 (67)	28 (72)	40 (70)
4. Prefer friends to SWD	3 (17)	8 (20)	11 (19)

In table 8.4, elderly participants' views concerning carer independence were in apparent contradiction to responses regarding the preferability of formal care versus family care. Whilst high proportions preferred not to ask their families for help, **44 per cent of participants believed that families should care for their elderly kin unaided.** This particular result was also in stark contrast to participants' consideration of familial attitudes to asking for outside help where not one elderly care receiver agreed that family members were opposed to extra-familial support in the provision of care. These results imply that there was a difference between what elderly people did in order to secure help and what they desired in terms of the form that help should comprise: they preferred to ask for help from the SWD rather than from their families yet simultaneously believed that families had a responsibility to care. This apparent contradiction in the results may have reflected the underlying disinclination elderly respondents expressed in terms of being "dependent" upon their families.

Table 8.4: Promotion of Caregiver Independence

Statement	Men n=18 (%)	Women n=39 (%)	Total N=57 (%)
1. Family is proud to care with little help from SWD	8 (44)	16 (41)	24 (42)
2. Family should care and not request assistance	9 (50)	16 (41)	25 (44)
3. Family thinks they should care unaided	-	-	-

Finally here, Table 8.5 reveals the views held by elderly participants about the duties of government to elderly people and the public provision of community care services. Over half of the elderly participants agreed that they would use more (domiciliary) services if they were available. In the light of previous results, this finding is not terribly surprising. For instance, table 7.3 in the previous chapter revealed that over a third of elderly participants thought they received "too little" home help provision. There was also widespread support for the increased public provision of social care services: 78 per cent of male and 64 per cent of female elderly participants agreed that the government should provide more social services to help families care for their elderly kin. For men, this belief in public provision was reflected by the other result that only 6 per cent agreed with the statement that "it is not the government's responsibility to take care of me." For women participants, however, the equivalent statistic was a far greater 41 per cent. suggesting that they were less politically inclined than men to attribute primary importance for the support of elderly people to public welfare policies. Whether or not this notable difference reflected gender-differentiated national insurance and taxation contribution histories or gender-differentiated attitudes to social services receipt was outside the remit of this study. For now, all that can be said is that it brought into focus again the finding that elderly people, in this case elderly women in particular, were uncomfortable with being seen as "dependent" upon formal agencies.

Table 8.5: Acceptance of Government Services

Statement	Men n=18 (%)	Women n=39 (%)	Total N=57 (%)
1. Govt. has no resp. to care for me	1	16 (41)	17 (30)
2. Would use more services if available	9 (50)	20 (51)	29 (51)
3. Govt. should fund more services	14 (78)	25 (64)	39 (68)

Table 8.6 below illustrates the distribution of scores achieved for each of the five components that comprise the Inventory. By way of reminder, the maximum possible score is noted in parentheses. The results reveal that the most positive sentiments elderly participants' expressed about formal services concerned the lack of either social or familial stigma that accompanied the use of domiciliary services. Confidence in formal services was also high and over half (51%) of respondents scored 4 or more out of a possible 6 points. With regard to users' preference for informal care over formal care and advocating of carer independence, the results were rather more equivocal and revealed a greater divergence of opinion amongst respondents. Finally, the respondents exhibited strong support for the public provision of social care services.

Table 8.6 Total Inventory Scores by Construct

N=57

CONSTRUCT SCORE %	0	1	2	3	4	5	6
1. Concern for the Opinion of Others (5)	16	3	0	5	16	60	
2. Confidence in Formal Services (6)	11	3	3	32	19	23	9
3. Preference for Informal Care (4)	12	14	32	17	25		
4. Belief in Carer Independence (3)	18	19	42	21			
5. Acceptance of Government Services (3)	18	19	28	35			

Each of the items in the Inventory reflected a positive or negative attitude regarding formal services and the coding system allowed for amalgamation of individual responses. For instance, for item 1 in table 8.5 immediately above, if the respondent agreed with the statement that, "It is not the government's responsibility to take care of me", a score of zero was recorded. Alternatively, if the respondent disagreed with the statement a score of 1 was recorded because this indicated a positive attitude towards formal services. In this way therefore, respondents scored from zero to 21 on the Inventory. At the extremities respondents were showing support only for informal care (score of zero) or only for formal services (score of 21): in the middle ranges, of course, respondents exemplified support for both sources of care.

Overall, however, respondents' total Inventory scores were skewed in support of formal services: **only 11 per cent of respondents scored 7 or less, 47 per cent scored from 8 to 14 while a further 42 per cent fell into the "high" support category of 15 or more.**

Generally therefore, service users' attitudes towards formal services were complex and multidimensional and centred around relatively high expectations for family

care. This resulted in certain contradictions among individual items on the Inventory. For instance, care receivers found formal services very acceptable despite a preference for family care, but even when they stated a preference for formal care over family care they also lacked confidence in those formal services:

> Aye well, the man and the woman, your son and your daughter, are both working now. In fact, it can be a bit of a problem for them to look after their old folk now because it's a seven-day week, 24 hours a day. So you might not want it, but you need the other help now.
> Respondent 132

> A stranger could probably give me better help than my two. Young people don't bother about themselves, let alone their people....But the home helps, they're only here for the money. I've heard two or three say that they do nothing when they go in.
> Respondent 111

Such complexities in elderly people's attitudes towards family care and formal services require much further analysis than a simple battery of attitudinal questions such as those posed here. The contradictions in elderly people's opinions uncovered here suggest that while elderly care receivers hold a high opinion of formal services in terms of their acceptability and quality vis-à-vis family care, they remain predisposed to the notion that families have a normative responsibility to care for their elderly kin. Such conclusions accord with existing orthodoxy: elderly people hold normative expectations about their families and the care they should receive from them (Finch and Mason, 1990), yet they also reveal that such expectations do not necessarily exclude support for the public provision of services. In other words, it would seem that care receivers themselves expect families and formal services to "share" care provision: whether such sharing occurred in practice and whether it was via a strategy of supplementation or complementarity provides the next topic for investigation.

Interaction Between Domiciliary Services and Family Care

a: Home Helps

In order to examine whether expectations were matched by experience, elderly participants were asked a number of questions designed to provide an overview of the organisation of the joint provision of care by families and domiciliary services. The focus of the enquiry here was any instrumental support they received from their families and domiciliary services: any emotional support elderly participants gained from either source was ignored at this point in the interview. This approach may be justified in terms of the primary need to gather data which described the interaction between family and formal care. Data which clarified the differences between the meanings care receivers attached to the different sources of care are examined in detail in the next chapter.

The types of domiciliary services received by the elderly participants placed major emphasis upon the relationship between home help provision and family care: 95 per cent of all respondents received home helps. Of the 54 elderly people who received home help provision, almost three quarters **(74%) stated that prior to their introduction they personally took major responsibility for housework.** Only a fifth of respondents indicated that their housework was previously undertaken by a family member. For purposes of interpretation here, it is pertinent to recall that just under half of all elderly respondents (46%) stated that they received more help from non-family than family carers. Furthermore, of these 26 elderly participants, the great majority (81%) had previously nominated their home helps as their major carers, while an even higher percentage (85%) stated that they had personally undertaken major responsibility for housework prior to their receipt of any home help provision.

These results are significant: they further repudiate the notion that the introduction of home helps replaces existing family care. Rather, the data suggested that home helps were introduced either prior to, or concomitant with, the onset of family help

with housework. This conclusion was strengthened by the finding that **81 per cent of the 54 home help recipients stated that this service had not affected the amount of family care they also received**. Only 15 per cent of elderly participants indicated that their receipt of a home help was accompanied by any decrease of family help.

Interestingly, not one elderly respondent identified any increase in the amount of family help they received since first receiving home help provision. In the light of the complaints made about reductions and cuts in the levels of home helps reported by elderly service users and carers alike in the previous chapter, one might have assumed that family carers were forced to "fill in the gaps": not only do chronic ailments invariably deteriorate over time but carers themselves indicated that service cuts resulted in an increase of their caring contributions. There was a contradiction here therefore between the responses of carers and those of service users. While elderly participants denied any increase in the amount of family care they received since first receiving home help provision, carers stated that their caring contributions had increased since this time. This represents a potential subject for future research; research which might benefit from a longitudinal perspective so that any fluctuations in dependency status and service levels may be pinpointed exactly in terms of any effect upon levels and types of family support provided.

Such is the political sensitivity and popular profile of the substitution hypothesis that it is important not to overlook any evidence of a substitution effect between family care and formal care, no matter how slight. Of key interest here therefore is that further examination of those fifth of respondents who stated that responsibility for housework prior to the introduction of home help provision lay with a family member reveals a gender bias. In fact, 29 per cent of all male respondents with home help provision indicated that a family member (including wives), undertook major responsibility for housework previously in comparison with 15 per cent of female recipients. This result suggests that the greatest risk of substitution of family care by formal care exists amongst male service users who

are more likely to have been "looked after" by their wives prior to home help provision than women are to have been "looked after" by their husbands. This conclusion provides an introduction to one of the most exciting topics under current exploration within the fields of social gerontology and gender studies: "connecting gender and ageing" (Arber and Ginn, 1995).

Respondents were also asked to describe the organisation of care as delivered by both home help(s) and family carers in order to provide an insight into the mechanics of the joint provision of care. Specifically, respondents were asked:

> Once here, does the home help do the same sort of housework as your ..... (main family carers) or does s/he do different things?

Respondents provided open ended responses to this question which were recorded verbatim. The coding protocol examined two aspects of the family care-formal care interface as described by care receivers: an overview of the tasks undertaken by family carers and formal carers; and a codification of the interaction effects which accompanied the division of tasks.

Responses revealed six patterns of activities in the tasks undertaken by the two sources of care. First, participants' descriptions revealed a pattern in which only home helps took responsibility for instrumental tasks. There was no family support whatsoever and respondents were also unable to participate in the tasks undertaken by home helps because of their disability:

> I've no family here, hen. The home help comes in at 8 and she does my bed. That's the best time for me. At the weekend they come in at 10. And then she does the washing up, the bathroom and the kitchen; she tidies up my mess *(laughs)* and gives me a row if it's too bad! But they're no allowed to do certain things. It's nuts; who else is going to do it? They cannae clean your windows or change a lightbulb. But who can do it if you've no one? Respondent 102

> If I discovered I need a tin opened and I forget to ask (*home help*), I've nobody to help me. On a Monday no one comes in and because I'm sick so often I have to swap between the two beds because I can't use the one because I've been sick all over it. And I can't ask my friend to clear that up. Mind you, she's a very good home help. It's not her fault the hours have been cut an hour.
> Respondent 134 (The problem with vomiting was a consequence of chemotherapy).

Second, elderly participants' replies revealed how home helps assumed the bulk of responsibility for cleaning while family carers took more responsibility for the personal care required:

> What happens is that on a Monday, the home help she comes in at 11.30 and then during the rest of the week she comes in at 8.15 until 9.30 and then the other days *(the weekend)* she's in at 7.45 for an hour and a half. ... (*Daughter*) gives us our breakfast and helps gets us dressed. The home help helps my husband get dressed because he won't have (*daughter*). And then she (*home help*) washes up and makes the bed and if there's time she'll hoover and give the place a dust: she tries to cover quite a bit. When Sheila gets back from work, she prepares the tea and during the evening helps me with my toileting. She (*daughter*) gets me ready for bed; my husband can usually do himself. She *(daughter*) gives me a bath on a Monday night, usually.
> Respondent 136

Third, respondents described how home helps assisted with cleaning, shopping, laundry and other daily household chores whilst family care involved help of a non-personal nature such as financial management and transportation:

> The home help does all that's necessary around the place and makes my lunch. Sometimes my son will make my lunch for me that the home help should have done but that's because she's been held up at some other place. And then my son collects my pension for me and sees that the bills are paid.
> Respondent 114

> My friends (*no family locally*) will take me out if I need to go and will get my milk and papers and rolls every day. The home help, well he just does around the place here that you see.
> Respondent 118

Fourth, the care receivers described how both formal care and family care were limited to housework:

> My daughter has to come every day. All she *(home help)* does is the kitchen: she hoovers the carpet in the kitchen and in here. My daughter does the same every other day of the week except on Thursday when the home help comes. My daughter does everything they're not allowed to do. I get a man to do the windows outside; my daughter does the insides.
> Respondent 138

Fifth, the respondents described a scenario in which formal care was limited to housework while family care was far more extensive:

> On a Monday she *(home help)* comes in about 8 o'clock and takes the washing to the centre *(respondent lives in sheltered housing)*. Then after she sees to my neighbour, she comes back at 9 o'clock and gives me a hoover (sic). And then on a Wednesday she comes and gets the lines for my messages and goes to the co-operative. The fish man comes on a Tuesday and the butcher comes on a Friday. And then my son and his wife comes on a Thursday with my pension and my daughter-in-law takes away my jerseys and anything big to be washed. And then I see my daughter-in-law again on a Saturday and she does any heavy work for me. She takes the duster round the ceilings and that, and she cleans the fridge and cooker or anything like that when it needs doing. And she changes my bed for me.
> Respondent 135

> The home help does the vacuuming and the stairs one day and the next day she'll do any ironing I have. That keeps her going the hour she has: she's a good worker. My son does any alterations and electrical things that need doing. And he regularly takes me out for a meal. I try not to worry them: if I've been to the doctor or anything, I don't tell them. And with my other son I have my meals there a lot. And with the other son I go to stay over for a couple of days or even a week. And my eldest son comes every Saturday and we go up to (supermarket). I wouldn't differ between either of them though; they all want to help.
> Respondent 141

Finally, respondents described how they themselves were the major participants in any joint provision of care with home helps rather than any family carer:

> I do the dusting, she *(home help)* does the hoovering and washes the bathroom and kitchen floors. I don't drive now so I can't carry a lot of shopping at a time, so I do some every day. It takes me out as well.
> Respondent 104

> On a Monday she (*home help*) collects my pension. And on a Friday she comes in for my lines for the messages and does that. She does no cleaning at all; no housework. It's all carpeted and I can manage the hoover except maybe once every two months when Mrs ....comes (*a friend*), she'll move the bed out and hoover under. And my neighbour is very helpful; she'll help me put up curtains and that. That superintendent (*home help organiser*) said to me: "Now are you sure that's all you want?". And I said yes because I don't see any need for her. To be truthful, it's only me here; there's not a lot to do. The flat is compact: it's easy to run. And after all, I can't sit and twiddle my fingers: it's not my nature to do that.
> Respondent 147 (93 year old woman living alone).

These descriptions of the ways in which housework is divided between home helps, family carers and care receivers prompted the fivefold classification of interaction between family care and formal care illustrated in table 8.7.

Table 8.7: The Relationship between Formal Services and Family Care

Interaction Effect	Men n=14* (%)	Women n=36** (%)	Total N=50 (%)
Substitution of family carer by formal care	4 (29)	4 (11)	8 (16)
Supplementation with family carer	2 (14)	7 (19)	9 (18)
Complementarity with family carer	3 (21)	9 (25)	12 (24)
Independence	-	3 (8)	3 (6)
Complementarity with elderly participant	5 (36)	13 (36)	18 (36)

* 4 cases missing

** 3 cases missing

Substitution was recorded when there was evidence of any replacement of family care by formal care:

> My husband was trained in the hospital to help me with this stoma, and how to get me into the chair for the bath. He (*husband*) likes cooking; well he does it all. Initially after this (*colostomy operation*) he managed on his own to do everything, but I complained about the house not being as it should; he's not all that good a housewife. But I don't know what I'd do without him. So that's when we got the home help, to do the housework because he was finding it too much. We used to have a home help three times a week but they cut it down to once for two hours. And the home help itself has changed; they're supposed to be more carers than cleaners. You see a lot of it depends upon the home helps themselves; some of them will do things and others won't. I've had four or five home helps and they've all been different like that.
> Respondent 139

Table 8.7 reveals that only 16 per cent of elderly participants provided any descriptions of the substitution of family care by formal care. Although the gender bias towards men should be noted, the general absence of any substitution further repudiates the notion that the introduction of formal care replaces existing family care. Far more common were instances of "shared care" between family and formal care. Almost half the elderly respondents (42%) indicated that the help they received with housework consisted of work undertaken by both home helps and family carers. In the first pattern, supplementation, formal carers and family carers undertook the same household tasks. A home help would clean the kitchen floor on a Monday but so too would a daughter on a Friday:

> Well even after the girl (*the home help*) has been here, if there's a spot of dust, she'll (*daughter*) get out the hoover. She keeps saying I should get them to do more. Well the home help is really here to do the hoovering and the floors, but my daughter does it as well. The home help does the hoovering in here, the hall and the big bedroom. It doesn't take half an hour mind you; I enjoy a good blather! But my daughter thinks the home help should do more but I tell her to leave them alone. So she (*daughter*) goes round repeating what they do.
> Respondent 124

An important point here is that this supplementation apparently involved an ineffective harnessing of the joint sources of care: home helps and family carers merely duplicated each other's efforts. Such duplication may have resulted from a perceived inadequacy of formal services on the part either of the elderly participant or their family carer. As such therefore, supplementation is an

interaction which highlights the importance of formal reassessment of service users' care needs and carers' abilities and preferences.

The second form of shared care revealed was a complementarity between formal care and family care. The two sources of care undertook different housework tasks which combined to provide a comprehensive coverage of all housework help required:

> The home help does the laundry, cleans the bathroom and cleans the kitchen. My daughters do the heavy housework. Betty does the main shop and Alison does the daily bits of shopping.
> Respondent 101

> She's (*daughter*) here every day and what the home help doesn't do, she does...all the washing and everything. I'm one of the fortunate ones. My daughter does it all; I couldn't have a better daughter, she's very good. My daughter's been helping me since I needed it after my husband died. I went on holiday with them (*daughter and son-in-law)* and it started from there. I always have my dinner there on a Sunday.
> Respondent 124

Such shared care is of course reminiscent of the interaction recommended by Litwak: although the tasks undertaken were different, they were collectively comprehensive and avoided wasteful duplication of effort. This complementarity mechanism suggests that each source of care was at least aware of the extent of the efforts of the other, even if it was the elderly participant who acted as the mediator between the two sources of support as opposed to any formal case management.

One significant divergence from the Litwak thesis however concerns the argument that formal care and family care were inherently suited to very different tasks. In contrast to formal care providing care of a more technical or complicated nature to family care, home helps performed the same mundane, repetitive household chores undertaken by family carers. The major difference was not the level of skills required, but the time in which individual tasks could be completed by home helps in order to keep within their service limits for individual service users. The data also revealed that health and safety at work regulations which applied to home

helps had the effect of simplifying the sorts of tasks they undertook as well as to enforce a situation whereby family care "filled in the gaps" that formal care left:

> She (*home help)* hoovers right through; the bathroom and everywhere. But they're not allowed to do the things we can't do! It's so funny. I've very good neighbours when my son can't do anything....And she (*home help*) washes the floor with a mop; she's no allowed to get down on her knees because of the rules again. It's so funny this, what they're not allowed to do...just the things that old people can't do either.
> Respondent 130

I've always

> But they (*home helps*) don't do housework, so I've got to do the best I can. I was on three times a week but they cut me back to two. And they're told not to do this and not to do that. So what happens is like last week, when my daughter did inside my windows for me...I need my daughter to fill in the gaps.
> Respondent 140

Since the time this data was gathered, the SWD has conducted an overhaul of the home help function including a move away from the provision of housework towards a model of personal care management. The most likely effect of such change is to increase elderly people's needs for housework; an increase which is most likely to fall upon the shoulders of family carers and which, if not met, can only result in the further creation and enlargement of care gaps.

Table 8.7 also reveals that a very small number of elderly care receivers (6%) described a situation whereby the provision of family care was independent of formal care: a scenario in which there was no communication between the two systems of support and no relationship between the care they provided. Finally, and perhaps most significantly, over a third of elderly participants **(36%) described the interaction between formal care and family care in terms of a complementarity between themselves and their home helps.** In other words, it was service users rather than family carers who participated in any relationship with formal domiciliary care:

> On a Tuesday morning my home help comes in and does the ironing plus some housework; usually she washes the kitchen floor. And then on a Friday she does my shopping. I do all the hoovering and I usually do the bathroom. But she (*home help*) will do the kitchen.
> Respondent 105

> I've got direct debit for all my bills, but I like to do my pension and then I get saving-stamps for my TV and telephone. My home help doesn't really do that much cleaning; she does the hoovering and I do the rest really.
> Respondent 128

This result reinforces conclusions about elderly people attempting to retain their independence for as long as possible. It also confirms the accuracy of the "triadic" definition of the family care-formal care interface introduced at the beginning of this chapter. The wording of the question used to gather this data deliberately stressed the joint provision of formal care and family care, yet elderly participants' replies stressed their own personal involvement in care management rather than that of their family members. Their perceptions of the interface between family care and formal care consisted of self-care efforts and formal instrumental support: a result which brings into focus the role of formal services in maintaining and improving the self-care capabilities of elderly people.

b. Other Services

Finally from the service user perspective, elderly participants were asked about the impact of day care services, meals on wheels and respite care upon the care they received from their families. Twenty seven respondents, (47% of the total sample), attended day care and a further five respondents, (9%), attended hospital day care on a temporary basis. Respondents were asked to explain why they had started to attend day care and whether their attendance had affected how much they saw their families. The coding scheme first revealed the identity of the person who suggested they attend day care and then addressed the reasons for that referral. Table 8.8 summarises the results.

Table 8.8: Reasons for Attending Day Care

Referral Point:	n=29* (%)
Self	1 (3)
Child(ren)	4 (14)
Social Worker/ Home Help Organiser	9 (31)
GP	7 (24)
Hospital Discharge	3 (10)
Don't Know	5 (17)
Reasons for Referral: Improve Social Life	16 (55)
Specialist Therapy	7 (24)
Carer Respite	4 (14)
Meals	1 (3)
Don't Know	1 (3)

* 3 cases missing

The numbers involved in table 8.8 are small and interpretation is therefore tentative but they highlight the predominance of social and health care officials as referral agents to day care. Sixty five per cent (65%) of respondents stated that a doctor, a home help organiser or a social worker referred them for a place at day care. By way of contrast, only four respondents indicated that their family carers had organised their places at day care and only one respondent stated that she organised it for herself. Over half the respondents (55%) said that their attendance at day care enabled them to meet other people, make friends and enter into a variety of different leisure activities. In other words, they attended day care for reasons of socialisation:

> It's a great thing. Like I said, the first day there they took me into the kitchen and told me to make buns! ... All the men congratulated me on the buns. It's great up there. They all call you by your first name and it makes it very friendly.
>
> Respondent 146

More significantly from the family care perspective, not one elderly participant said that their attendance at day care affected how much they saw their family. Even the four respondents who replied that they attended day care in order to give their carer a break failed to make any link between day care attendance and time spent with family carers. This result is intriguing: 41 per cent of those attending day care did so twice a week or more, (see chapter five). It would seem therefore, that care receivers held no expectations about the normative responsibilities of their family carers during the hours of their day care attendance. This in turn suggests that day care did indeed provide family carers with an opportunity for respite from their caring activities.

Of the eleven elderly participants who received meals on wheels, four stated that their main meals were previously prepared by their family carer and six replied that they used to do their own cooking. Once more therefore, the substitution of self care with formal care was more predominant than family care with formal care.

Finally here, of the ten elderly participants who had used respite care facilities, half replied that they used such facilities in order to give their family carers a break. Interestingly, another two respondents replied that the purpose of respite care was to provide them with a break from their normal routine, while a further two respondents used respite for post-operative convalescence purposes.

Despite the paucity of numbers here therefore, the results emphasised the importance of health professionals, (general practitioners, hospital consultants or medical social workers), in the referral process for day care: family carers made few attempts to access formal services on behalf of their elderly parents. The results also demonstrated that elderly people most appreciated these other formal services because of the opportunities they provided for an extra-familial social life.

The Carer Perspective

The family care-formal care interface was also addressed from the perspective of the 18 adult child carers in the form of four principal questions. The first question was:

> Can I just check, were you helping your father/mother before s/he started to receive any services at home from the Social Work Department?

Most significantly here, 14 of the 18 carers, indicated they had been caring for their parent prior to any receipt of domiciliary support:

> Oh yes, but Mum was able to do more then. She could put her own laundry in and hoover herself. But gradually, all that stopped. But we were coping for about a year on our own. Well, I was working at the time, but I was doing all the bills and financial things and my sister did all the practical things.
> Carer 101

> Yes. She was coming here to stay every weekend and I would help her with her bath and washing (*laundry*) then. And I was doing her messages and a bit of housework like her windows.
> Carer 129

> Yes, I started helping before my mother died...and then I just sort of carried on afterwards. There was a break when he (father) went off to Australia to see my brother, but apart from that I've helped for quite a while.
> Carer 132

This finding is in stark contrast to the equivalent result obtained from elderly participants. By way of reminder, when asked who undertook responsibility for housework prior to the introduction of a home help, 85 per cent of elderly participants replied that they had done so personally. In other words, the great majority of elderly participants considered themselves to be self-reliant prior to receiving home help support. This disparity suggests that the two groups held different views about the commencement and constituents of family care: adult children considered themselves to be "caring" for elderly parents while elderly parents considered themselves self-reliant. Furthermore, adult children attached the

label of "care" to activities such as inviting parents for lunch on Sundays or undertaking housework upon an ad hoc basis while elderly parents did not identify these tasks as "care" at all.

Of course, the evidence presented in chapters three and four demonstrated the reluctance of elderly participants to regard themselves as dependent upon others and indeed demonstrated their determination to conduct their own affairs despite severe functional difficulties. As such, this disparity in the accounts of carers and their elderly parents regarding the provision of family care prior to the receipt of formal services may have resulted from elderly participants' denials of dependency. But the question posed to elderly respondents made no reference to "dependency": it simply asked for the identify of person(s) who undertook major responsibility for housework prior to any receipt of home help support.

The result that the overwhelming majority of elderly people (85%) replied that they undertook responsibility for their own housework therefore suggests that carers and care receivers did not share a common conceptualisation of family care. Carers and "care receivers" understood different things and drew different conclusions from the practical aspects of their relationships. Of course, these results related to the time before home help provision was allocated and thus in many cases to several years prior to the date of the interview. Nevertheless, carers were more likely than their parents to identify "care provision" in their dealings with their elderly parents prior to the allocation of domiciliary services.

This result is pertinent to a concern which informed this study; the research attention paid to self-defined "primary carers" and oversight of the experiences of care receivers. The disparity between carers and their elderly parents evoked different perceptions regarding the relationship between family care and formal care. For instance, elderly participants' descriptions of the ways in which family care and formal care combined (table 8.7 above) highlighted their continued involvement with household management and thereby emphasised the interaction between formal service providers and service users. By way of direct contrast, the

fact that 14 of the 18 carers stated that they were caring for their elderly parents prior to any formal domiciliary support focuses attention upon interaction between family carers and service providers.

In order to investigate this issue further, three additional questions were addressed to carers. Firstly:

> And do the services your father/mother receives from (*the SWD*) affect you and the help that you give him/her in any way?

Carers' responses emphasised the practical benefits they accrued from their parents' receipt of domiciliary support. For instance, 12 carers replied that domiciliary services reduced the level and scope of practical supports they needed to provide:

> Aye because if she didn't get the daily help, we'd have to do the things she (*home help*) does. Basically, we haven't got the housework and of course the meals-on-wheels too...for two days a week we don't have to worry about what Mum has (*to eat*).
> Carer 101

> Well if it wasn't for the home help there would be all the cleaning and washing to do...it makes it much easier for me, otherwise, I'd probably have to go down every day and make his breakfast and his lunch too.
> Carer 114

Inherent in these statements was the identification of a substitution between filial care and formal care:

> I think it does. For example, the bathing side of things...I might have to do that sort of thing if the nurse didn't come in. I think I would have a lot more to do if these people weren't coming in...my wife too!
> Carer 116

There is a political concern here. The policy rhetoric of community care states that formal services are not intended to replace the efforts of family members and friends but to complement, improve and co-ordinate those efforts. Regardless of whether any direct substitution between family care and formal care had already

taken place, however, carers' replies stressed that formal services provided some part of the practical support they otherwise would have been required to give. Of course, we do not know the prognosis for family care in the absence of any formal support. Nevertheless, carers' replies highlighted the direct practical benefits domiciliary services provided to them via a rhetoric of substitution: the home help did what they otherwise would be obliged to do.

Interestingly, only one carer made any mention of how the provision of practical support via domiciliary services enabled her to spend more "quality" time with her mother:

> Well, if it wasn't for the home help, I'd be having to do the cleaning. But with the home help being there, I can sit and talk to my Mum when I go (to visit). But it makes me feel very guilty seeing someone else do it. But as the lady says, that's her job; that's what she's paid for.
> Carer 109

The rationale used by the six carers who did not refer to any practical benefits they accrued from their parents' receipt of domiciliary services was most commonly based upon the time limits allowed to home helps:

> Not, not really. All the home help is, is company for her for an hour and a half. I think she's just supposed to do housework, which she does after a fashion. Of course, my mother's a blather; she likes to sit and talk to folks. But I work pretty independent of (*the SWD*): she only gets an hour and a half a week.
> Carer 124

> Well, quite honestly it doesn't affect me. I'm quite glad that they (*home helps*) light the fire because I don't like to light fires and I suppose I'd have to go there the back of seven, possibly earlier in the winter, if they didn't do it. But I spend nine hours a day there as it is, so the services...don't really affect me.
> Carer 129

These particular carers considered the levels of services received by their parents to be negligible in terms of total supports their parents required. This meant that they undertook responsibility for the majority of care tasks and, as such, derived little sense of respite or relief from their filial caregiving responsibilities despite the domiciliary services provided.

These six carers aside however, results revealed that domiciliary services reduced the amount and types of care the majority of family carers deemed necessary. In order to quantify the relationship between family care and formal care more explicitly however, carers were next asked:

> More specifically, would you say that the services your father/mother receives from (the SWD) has increased, decreased or not affected the amount of help you give him/her?

Not one carer replied that their parent's receipt of domiciliary services had increased their caring contribution. Rather, their replies were evenly divided between the other two options: exactly half the carers replied that domiciliary services had not affected the amount of help they provided their parents; the other half replied that services had reduced the care they tendered.

This finding was in contrast to that produced by the previous question. Two thirds of carers described the effects of domiciliary services upon their caregiving in terms of limiting the care activities they were required to undertake, yet one half simultaneously replied that domiciliary services had not reduced the amount of care they actually provided.

The explanation offered here is that although carers pointed towards domiciliary services as "saving them" from undertaking certain chores, the total volume of care needs increased over time because of the progressive nature of chronic illnesses. This means that carers were unable to reduce their concomitant caring contributions because of relatively low and not infrequently reduced levels of domiciliary services.

Finally, carers were asked:

> And how does the help you give your father/mother differ from the help they receive from (the SWD) services?

The results illustrated that carers drew a clear distinction between the support they provided their elderly parents and the help their parents received from domiciliary workers. Their most common response drew attention to an emotional superiority of filial care over domiciliary care. Thirteen of the 18 carers stated that their care was better than that organised by formal domiciliary services because of the emotional bonds unique to kinship:

> I do as much for her as any one person could possibly do. But, (the SWD) will be more detached than I would. Oh, they have compassion and they are dedicated and interested in old people; you couldn't do that sort of work if you weren't. But it's just a patient to them: they don't have the emotional side of it. It's not a relative, so they would feel less stressed out, less guilty if things went wrong. At the end of the day, they are just doing a job.
> Carer 100

> It's the emotional thing. We (*respondent and her sister*) can give her moral support and take her to places that she otherwise wouldn't get to...like the bingo and up the town and that. And she can probably talk to us more than she could a home help or any other of the helpers.
> Carer 117

Furthermore, ten carers referred to the individuality of their care in comparison with domiciliary care. Their support was tailor-made to fit their parents' requirements:

> Mostly, well I'm like her personal chauffeur; driving her when and wherever she wants to go. And also getting her messages. I'm on hand most of the time in case anything goes wrong. I don't see how (the SWD) could do that for her.
> Carer 121

In other words, carers indicated that the biography they shared with their parents produced a caring relationship which was better emotionally and different practically from formal care. As such, their responses add emphasis to the

difficulties faced by researchers acknowledged at the beginning of this chapter: it is difficult to compare family care with formal care because of inherent differences in content, motivation and meaning. From the perspective of the family/formal care interface, however, carers' responses highlighted two main forms of interaction: substitution and complementarity. They first acknowledged that formal services substituted for tasks they otherwise would have been obliged to provide but also explained that the nature and content of the care they provided was unique to their relationship with their elderly parents and, as such, quite different to that which could possibly be procured through formal domiciliary care

Conclusions

This chapter has been based upon three observations: community care represents the systematic mechanism through which family care and formal care may be linked; a host of analytical frameworks conceptualise this linkage; yet there is a dearth of data which describe such links at the site of care provision. The aim of this chapter therefore has been to describe the relationship between family care and formal care as described by elderly care receivers and their filial carers.

The first part of the analysis examined the opinions of elderly care receivers' towards using domiciliary services and their relative merits or deficits as compared with family care. The results revealed that elderly participants attached negligible social stigma to their receipt of formal services and held a high degree of confidence in the service system. Their attitudes towards the duties of families regarding the care of elderly relatives however were in contrast to their preferences regarding the source of support. Elderly participants in general, and male respondents in particular, were reluctant to request care from their families despite the fact that a large minority of them (44%) simultaneously expressed the opinion that families should care for elderly relatives unaided. Overall therefore, the data illustrated that while elderly service users held a high opinion of domiciliary services they remained predisposed to the notion that families had a normative

responsibility to care for elderly kin. In other words, elderly service users expected their care to be shared between formal services and family members.

The way in which formal care and family care actually interacted at the site of care provision was examined from both care receiver and carer perspectives. Their respective descriptions provided various divergencies of opinions. Most notable was the difference regarding the provision of family support prior to the delivery of domiciliary care: 85 per cent of elderly respondents stated that they undertook their own housework prior to receiving a home help while 14 of the 18 filial carers interviewed stated that they previously helped their elderly parents. Furthermore, with regard to contemporary interactions between family care and formal care at the site of care delivery, while family carers highlighted the interaction between themselves and domiciliary workers, elderly service users also detailed the links between self-care and formal care. Thorough evaluation of formal services should therefore involve both parties to the caring relationship and not just focus upon the experiences of carers.

The other notable discrepancy in opinion between elderly care receivers and their filial carers concerned their qualitative comparisons between family care and formal care. Over half of the elderly respondents stated that domiciliary workers could take as good care of them as their families while carers stressed that their caregiving was best distinguished from domiciliary services in terms of emotional and affectual underpinnings. Once again therefore there was an asymmetry between the experiences of carers and care receivers; an asymmetry which can only be balanced when both parties to the caring relationship are included in analysis.

9

THE MEANING OF FAMILY CARE AND DOMICILIARY CARE

Introduction

"Caring" is a complex and multi-faceted concept: the meaning of care and the activity of care are fibres of the same fabric but woven into a design often difficult to disentangle. Furthermore, care is a central concept for social policy. Not only is the concept and experience of care integral to the way in which we understand ourselves and our relationships with others, it is a key function of social welfare agencies. Recognising the multidimensional nature of care in this way is straightforward enough; the analysis of care however is fraught with difficulty.

The term "care" evokes notions of identity and activity, thinking and doing, "labour and love". As such, researchers indicate that "care" warrants conceptual development and empirical examination (Baldwin and Twigg, 1991 p117). A key feature of the effort to decipher care concerns examination of its multiple material, social, biographical and affectual foundations; distinctions epitomised most simply in terms of the differences between caring for and caring about a person (Ungerson, 1983). With this in mind, an oft-quoted definition of care is that it is:

> ...a concept encompassing a range of human experiences which have to do with feeling concern for, and taking charge of, the well-being of others. Graham, 1983, p14.

In other words, caring is a universal human experience: we all need to receive care and to give care. The mapping of "care" however reveals that its provision is correlated to specific social relationships; most particularly those pertaining to the family and the home (Graham, 1983). Within these settings, and with few

exceptions, (e.g., Green, 1988; Arber and Gilbert, 1989), care is associated materially and ideologically with women in their roles as wives and daughters.

The conceptualisation of care provides a major focus within the feminist caregiving literature (e.g., Dalley, 1988; Finch, 1984; Graham, 1983, 1991; Thomas, 1993; Ungerson, 1987). Expressed most simply, this literature addresses the intersections between behaviour, normative beliefs and material circumstances as they affect the provision of women's care. This last point is significant: the conceptualisation of care has been based upon the axioms and effects of its provision. With few but notable exceptions (e.g., Aronson, 1990; Evers, 1985; Morris, 1992 and 1992b), the feminist conceptualisation of care overlooks the experiences of those receiving care. Consequently:

> The inner experiences of the older people stand out as requiring exploration. How do they feel, what are their reactions and their perspectives when they are dependent on adult children? They are the ones who fear becoming "a burden" on their children. What effects do they experience when their fears become reality?
> Brody, 1990, p257.

The main defence for the unilateral perspective adopted in the feminist literature is that informal care is a vital topic of concern for women. It raises a host of difficult questions about the domestic division of labour, the relationship between the family and the state, the organisation and delivery of formal health and social services and the role of nurturance in women's lives. Furthermore, the concentration of analysis upon care provision reflects analysts' recognition of the difficulties encountered by family carers under the contemporary policy of community care: policy whose rhetoric is preoccupied with methods of cost containment and whose practices are predicated upon the unpaid labour of wives and daughters (DHSS, 1981, p3).

Justification aside however, the unidirectional focus upon provision has produced a conceptualisation of care which is, at best, incomplete. More seriously, the focus serves to marginalise further the interests, needs and preferences of frail and

disabled elderly people themselves (Morris, 1992b, p157), while in the worst case scenario it sets the interests of disabled care receivers in direct opposition to those of carers (e.g., Finch, 1984, p7).

The previous chapter examined the instrumental family/formal care interface; it identified the "tending" provided by family carers and domiciliary workers and investigated their practical relationship at the site of care delivery. But descriptions of care which deal with practicalities alone ignore the significance that care recipients and carers attach to the variety of support delivered; they provide a partial overview of the ways in which family care and formal care "interweave".

The purpose of this final substantive chapter therefore is to explore the "meaning" of care from the dual perspectives of care receivers and filial carers. This exploration aims to highlight any qualitative similarities or differences care receivers and carers accorded to family care and domiciliary care. Specifically, the chapter comprises two main components: each respondent group's evaluation of the relative importance of family care and domiciliary care for a number of specified care outcomes; and their identification of the best and worst aspects of each source of care.

Deciphering the Concept of Care

The major limitation of the previous chapter is that it describes the "tending" formal and filial carers provide and ignores the "concern" carers have in their support of their parents (Parker, 1981, p17). "Care" describes far more than cooking and cleaning, washing and ironing, bathing and grooming. It involves: motive and emotion; perceptions concerning normative obligation and familial duty; distributive justice; benefit and cost. Practically, the components of concern and tending which amalgamate into "care" are conceptually and practically difficult to separate, (Parker and Lawton, 1994, p5). Unfortunately though, the caregiving literature is strewn with studies which treat them in mutually exclusive ways. The principal stations on this "twin track" analysis of care are empirical

mapping and the theoretical investigation of carers' activities and motives. As the majority of previous chapters have served to demonstrate, the empirical care literature is particularly prolific and concentrates upon the identity of carers, the nature of tasks they undertake and the effects of doing so. The theoretical agenda involves fundamental questions about the role of nurturance in women's lives, the way in which the family as a primary social group creates and sustains gendered "identities", and how social policies compound the feminine normative imperative to care (e.g., Land, 1978; Okin, 1989).

Mapping Carers: Activities and Consequences

Empirical research emphasises the feminine specificity of care via a "tri-cycle" perspective: child care, parent care and care of an aged husband (Abel, 1987 p18). It also provides numerous typologies of care according to the type of tasks undertaken (e.g., Horowitz, 1985; Brody, 1990; Parker and Lawton, 1994) and the identity and circumstances of the carer, (e.g., Green, 1988). Increasingly, researchers have been concerned to qualify the feminine specificity attached to care. The 1985 General Household Survey, (GHS), revealed there to be more male carers than previously supposed (Green, 1988), while official analysis of the 1990 GHS stated:

> "...the proportions of men and women caring are not markedly different - in 1990 13% of men and 17% of women said they were looking after, or providing some regular service for, someone who was sick, elderly or handicapped."
> (OPCS Monitor, 17 November 1992).

Of course, there are significant differences between male and female carers (e.g., Arber and Gilbert, 1989; Finley, 1989; Horowitz, 1985; Morris, 1985; Spitze and Logan, 1990). Most significant, the majority of male carers are spousal carers while women not only care for their disabled husbands but are more likely to care for disabled parents and non-relatives (OPCS Monitor, 17 November 1992). The familiar "hierarchy" of kinship obligations explains the precedence of spousal care over other kinship obligations and gender expectations (e.g., Cantor, 1979; Finch

and Mason, 1990; Shanas, 1979; Qureshi 1990; Qureshi and Simons, 1987). Indeed, even though Finch and Mason's innovative application of care scenarios lead them to substitute procedural "guidelines" for kinship "rules" (Finch and Mason, 1993 p9 and p166), the primacy of spousal care over all other formats of family care remains uncontested. Married men are expected to care for disabled wives in the same way as married women are expected to care for disabled husbands.

Spousal care aside, there are a number of recognised differences between the care provided by women and the care provided by men. For instance, more women than men are involved at the "heavy" end of care provision: two in every three of those caring at least twenty hours a week are women (Green, 1988). Furthermore, recent secondary analysis of the 1985 Informal Carers Survey illustrates that although as many men provide physical care as women, substantially more women than men provide personal care and a combination of physical and personal care (Parker and Lawton, 1994 p97). Finally here, the majority of women (over 70%) care for a relative (Green, 1988); a finding which provides an important link with feminist research addressing the ways in which gender differentiated processes of socialisation are apparent in family life.

The arduous, physically demanding, nature of caring for an elderly relative is similarly well documented and requires no elaboration here, (see Glendinning, 1992). More significantly, this knowledge prompts the realisation that family care is socially necessary work and that family care is a "social good" whose crude benefit to society may be calculated in terms of the opportunity costs of carers' salaries and replacement costs of public services. Indeed, by separating the provision of family care from the cash nexus, by regarding care only as an expression of women's "connectedness with others" (Graham, 1983 p26), researchers have been accused of sentimentalising what may otherwise be regarded as women's unpaid labour (Abel, 1987).

Evaluation of the "social good" notion of family care introduces the debate about the "costs" of caring (see: Rimmer, 1983; Baldwin, 1985; Joshi, 1987; Parker, 1990; Glendinning, 1992). Such "costs" include: economic, physical, emotional and opportunity costs; loss and restriction of employment; reduced income; increased expenditure; restricted family and social life; and emotional and physical strain (Parker, 1990 p57). Of course, significant policy interest also accompanies the "costs" of caring debate. Rightly or wrongly, health and social care planners generally regard community care as their cheapest policy option. For instance, one study "costing care" found that in situations where the dependent person lived with their family carer, public expenditure on community care services was less than half the amount required to maintain the same individual in hospital, (Wright, Cairns and Snell, 1981).

From a policy perspective therefore, it is highly desirable that family care remains the key ingredient of the community care recipe and that community care is, in turn, the main course on the long-term care menu. In keeping with such policy intent, the identification of carer burden and the costs of providing care furnish a rationale for the allocation of formal services in terms of supporting carers and prolonging their provision of care to elderly relatives (Twigg et al., 1990).

Contemporaneous to calculations concerning the "costs" of care is the debate about the commodification of informal care: a debate which generates a host of issues concerning the rationale, principles and methods of paying family carers (e.g., Baldock and Ungerson, 1991; Craig, 1992; Lingsom, 1993). The commodification of care debate is in its formative stages and there remains uncertainty as to whether payment represents an attempt to regulate the behaviour of carers or a reward for the work they perform and an alleviation of the financial burden caring may engender (Craig, 1992).

With regard to any regulatory intent of payment, it is by no means clear that any form of financial compensation provides carers with an incentive either to start caregiving or to continue caring for relatives with high levels of dependency and

thereby delay nursing home placement (Baldock and Ungerson, 1993). Carers do not operate according to the principles of economic rationality alone but also according to their normative beliefs and the strength of their emotional bonds with the disabled relative: they "negotiate" caregiving responsibilities (Finch and Mason, 1993). With regard to remuneration, however, the level at which payment is made becomes the critical issue. In particular, there is a concern that payment which reflects a carer's potential earnings, as well as payment pegged at social security benefit levels, will have a built in class bias in terms of take-up. Finally, there is the very real concern that the effect of paying family carers will be to bind women more tightly to the domestic sphere and thereby exacerbate the gendered nature of caregiving obligations (Lingsom, 1993).

Monetary matters aside, the remaining costs of care are physical and emotional costs. Actual causality between caregiving and carer physical ill-health remains to be proven (Parker, 1990 p79), but many studies demonstrate that carers suffer from their activities: they have been called "hidden patients" (Fengler and Goodrich, 1979). Archbold, (1983) refers to caring as a "progressive all-consuming" activity and carers themselves report a variety of negative consequences including physical and mental health deterioration (EOC, 1980; Levin et al., 1989), depression, role strain, role conflict, social isolation and disrupted domestic routine (Deimling et al., 1989). In particular, the literature talks about caregiver "burden" (Baldwin, 1985; Braithwaite, 1990; Cantor, 1983; Gilhooly, 1984; Gilleard et al., 1984; Nissel and Bonnerjea, 1982): the distress which results from dealing with a care receiver's impairment and in particular the "crisis of decline" (Braithwaite, 1990). The idea of burden links the needs, characteristics and functional status of the care receiver to the well-being of the carer (Poulshock and Deimling, 1984).

Furthermore, but without straying into definitional, causative and symptomatic controversy, "stress" is regarded as a common response to providing care. Indeed, "stress" has been identified among carers providing low levels of "semi-care" (Lewis and Meredith, 1988), and has been regarded as a "normative" response to

the strain of caregiving, (Brody, 1985). Despite its widespread occurrence however, stress is nevertheless a "subjective" cost of caring. Different carers respond in different ways to the same caregiving scenario; and while some carers will find a particular situation "stressful", others will not (Braithwaite, 1990). Furthermore, to imply that stress is universal amongst carers in the same way that one can calculate the financial consequences of caregiving is to deny that carers identify intrinsic rewards from their caregiving role and that they may regard caregiving as its own reward, irrespective of any other motive or outcome (Abel and Nelson, 1990; Ungerson, 1987). In other words, caregiving can be fulfilling as well as stressful and burdensome (Baldwin and Twigg, 1991 p124). Qualitative studies in particular confirm the "profound ambivalence" carers experience, (Lewis and Meredith, 1988, p138), and emphasise that carers are "often in self-contradiction and hence full of tension" (Ungerson, 1987 p141).

Explaining Care: Motives and Predilection

Imposing a subjective lens onto the panorama of carers' experiences and reactions to care provision serves a useful heuristic purpose because it provides a bridge to the other rail of the "twin track" conceptualisation of care: the theoretical examination of the "loving, thinking" components of care (Leira, 1993) and how they fit into the development of gender and creation of gender relations within the family. The research agenda here comprises questions about the construction of gendered "identities" (e.g., Baker Miller, 1976; Chodorow 1978; Okin, 1989), the role of nurturance in women's lives (e.g., Graham, 1983; Ungerson, 1983; Abel, 1990), and examination of the family as a primary source of gender inequality (e.g., Finch and Groves, 1980; Land, 1978; Land and Rose, 1985).

Social psychology explains women's predisposition and predilection to care in terms of the separate psychological construction of gender. For instance, Baker Miller (1976) relates the female traits of sensitivity, empathy and intimacy to women's subordinate position in a male-dominated society, and argues that this subordination explains women's psychological predisposition to act as carers. Put

simply, a women's sense of self is organised around being able to create and maintain relationships (Gilligan, 1982 p83), whereas the male ego is based upon competition and associated primarily with the labour market (Graham, 1983). A rather different slant on the gendered identity thesis is provided by Nancy Chodorow who adopts an "anti-essentialist" stance (she rejects the view that caring is a reflection of women's biological and psychic needs), and identifies the "assignment of primary parenting" as the way in which women, (mothers), recreate the personality types of male and female within their own children.

The weakness of the gendered identity thesis resides in its conflation of gender with sex: gender is divided into two mutually exclusive categories in the same manner as sex identity. In the same way that chromosomes determine whether a unborn child is male or female, the gendered identity thesis is founded upon a dichotomous organisation of personality traits into male and female (regardless of inherent nature versus societally produced origins). By implication therefore, any variation in the principles of societal organisation (for instance the introduction of collectivism and abandonment of the domestic division of labour) is unlikely to effect much change in terms of gender identity and activity. Furthermore, any rejection or dissolution of the gender prototype, such as may very well occur when "care labour" outlasts "care love", or when a woman refuses to leave the labour market in order to care in the home, is ignored. Finally, the gendered identity thesis defies reality: it overlooks completely the fact that some men do "care", both in activity-based and emotional terms. Theorists argue therefore that gender is better conceptualised as a continuum along which there are multiple manifestations and adaptations of each variety (e.g., Sevenhuijsen, 1992).

A more convincing explanation of "why women care" is offered by Clare Ungerson in her review of the "skills, tasks and taboos" of caring. She argues that powerful cultural motives operate in the sphere of caregiving and suggests that a gender-related system of taboos and expectations serves to sustain women's roles as carers. Indeed, these motives may even encourage women to choose to be cared for by another woman (Ungerson, 1983b). In other words, caring is a culturally

prescribed medium through which women achieve identity and kudos: it is learned behaviour, not innate.

Hilary Graham also rejects the "nurture is nature" thesis. Her argument is based upon understanding care as a construct which results from the network of social and economic relationships that operate in the home and workplace (Graham, 1983). More specifically, Gillian Dalley locates motherhood at the heart of the nature of care. Motherhood confuses biological reproduction with social reproduction: the function of bearing children and the emotional bonds associated with it become indissolubly linked with the tasks of servicing, maintaining and comforting children (Dalley, 1988, p9). By way of contrast, even though men might be expected to care *about* a relative, they are rarely expected to care *for* a relative (ibid., p11). Dalley concludes therefore that men are expected to provide the setting within which the provision of care can be offered by women. Finally, she argues that public policy develops and sustains normative gender expectations concerning care:

> ...the whole of community care policies can be seen to be based on the supposition that women are naturally carers, whilst men are naturally providers. And because such policies assume and presume the altruism of women, they reinforce that presumption.
> Dalley, 1988, p12-13.

This conclusion is reiterated by Ungerson who stresses that public policy determines the circumstances under which women's caring occurs and the "working conditions" in which women's care is delivered (Ungerson, 1990, p1). This latter observation reminds us that women's care is not confined to the domestic arena but is replicated in the labour market. Such replication helps to account for the segregated nature of women's paid work, a segregation which in turn acts to reinforce the domestic division of labour:

> Caring, it appears, describes more than the universal feelings women have; it describes the specific kind of labour they perform in our society.
> Graham, 1983 p25.

The concept of care is therefore primarily understood in terms of women's social, economic and ideological experiences: it can be neither abstracted from these experiences nor objectified. There is a causal link between women's caring, their material conditions in the home and labour market and the pervasive ideology which attributes normative responsibility to women for the provision of care (Ungerson, 1983, p49). In other words, normative social processes involving material and ideological factors concerning kinship obligations and sex-role differentiation are responsible for the feminine specificity of care (Ungerson, 1987, p34).

Despite the plethora of research outlined above, conceptualisation of the origins, organisation and outcomes of care provision remains an under-theorised area (Thomas, 1993). In particular, the constructs of class, ethnicity and age are missing from the analytical framework (e.g., Graham 1991). Most importantly here, however, the conceptualisation of care needs to be extended to include the needs, experiences and preferences of care receivers. The conceptualisation of care in terms of a provision-only focus overlooks entirely the fact that care occurs between, and is experienced by, two or more people. The concept of care cannot be abstracted from the relationship in which it is embedded: indeed, it only makes any sense when defined in terms of that relationship. A comprehensive conceptualisation of care needs to chart the relational contours that exist between carer and care receiver. At the very least, it should encapsulate the variety of needs, preferences and experiences of care receivers in order to shed light on the effectiveness of the caring relationship.

Incorporating Care Receipt into the Conceptualisation of Care

There are important reasons for incorporating the experiences of care receivers into any conceptualisation of care. The first concerns the observation made in both chapters three and four that elderly people are often reluctant recipients of care. No matter if the help they receive derives from formal services or family members, elderly people exhibit strong behavioural and attitudinal support for self-capacity

and independence. This may well be because they are subject to a strong cultural injunction to retain their "independence" and not to make unacceptable demands upon their families, (Aronson, 1990). It also suggests the possibility however that care receivers, just like care givers, experience "profound ambivalence" and a gamut of other contradictory emotions about the care they receive.

I am suggesting that there are complex, but thus far uncharted, boundaries around the types and levels of care that elderly people desire and are prepared to tolerate. The data presented in chapters 3, 4, 7 and 8, illustrated that elderly people were not passive recipients of care, but had real preferences about who their carers should be and the sorts and levels of care they required, desired and were prepared to tolerate (also Arber and Ginn, 1991). Of course, as chapters 4 and 7 in particular revealed, care arrangements were often determined more by practical limitations than personal preference and demand. Nevertheless, this study has produced sufficient evidence to demonstrate that family care is effectively "negotiated" and that the actions, preferences and demands of elderly care receivers may serve to jeopardise as well as to enhance the effectiveness of care ultimately fashioned (Finch and Mason, 1990, p152).

The second reason concerns the ways in which the characteristics of the care receiver and their relationship with their carer(s) impact upon the types of care delivered, the effectiveness of that care and the mutual well-being or otherwise of both parties. In particular, the relationship between the well-being of the care recipient and that of the caregiver is far from understood in the caregiving literature. To date, research has addressed the negative effects of care provision upon caregivers; a scarcity of data documents the impact of care upon care receivers (Evers, 1985). Indeed, it is not unfair to state that the general assumption held is that the well-being of the care receiver is at the expense of the caregiver. This assumption results in the relationship between care receivers and care givers being understood in adversarial terms and helps develop a scenario in which the interests of one group are pitted in direct opposition to those of the other. Such antagonism inherently disregards any possibility of interdependency between care

receivers and their family carers, assigns a marginality to elderly people in terms of their contribution to family life and overlooks the format and prevalence of intergenerational reciprocity and exchange.

The third reason for including receipt in the conceptualisation of care relates to the development of sympathetic social policies. The research challenge is:

> ...to articulate a platform which responds to the interests of both caregivers and care recipients.
> Abel, 1987 p27

The conceptualisation of care therefore should view the dependency of the care recipient in material, instrumental terms. Ethically however, the conceptualisation of care needs to recognise and validate the autonomy of the care recipient:

> Both parties in a caring relationship, carer and cared for, are entitled to moral autonomy, self-respect and integrity. For both parties the caring relationship may require that personal identity is positively or negatively confirmed.
> Leira, 1993, p27

In order to validate the right to such moral autonomy, researchers need to interpret more fully the diversity and similarity of experiences which accompany not only the giving but also the receipt of care. In particular, researchers need to examine how these experiences are perceived and interrelated within the social and economic circumstances of both parties to the caring relationship.

One way to incorporate receipt into the conceptualisation of care is to focus upon the relationship that exists between carer and care receiver. Another is to recognise that care receiver characteristics and resources may intervene in either negative or positive ways to influence the outcomes of caregiving. Both suggestions are founded upon the principle that the conceptualisation of care must include the experiences, interpretations and preferences of care receivers:

> Caregiving research, just as research in the field of aging (sic), has started out in search for commonalities which underlie the caregiving process...increased attention is (*now*) directed at diversity in the process and outcomes of caregiving based on the different populations of caregivers and care-recipients.
> Kahana and Young, 1990, p76.

This study contributes to a widening of the conceptualisation of care via a comparison of the meanings that care receivers and filial carers attached to the different sources of care received and given. This comparison is an exercise in increasing the vocabulary of the "language of care" (Ungerson, 1990) and draws attention to the gamut of emotions and material circumstances which best described elderly people's experiences of receiving care.

The Study Data

a. Comparisons of Family Care with Formal Care

By way of introduction to the meanings care receivers and carers attached to family care and formal care, both respondent groups were first asked to evaluate the relative importance of the two sources of care. Their evaluations covered the commonly stated instrumental, emotional and social purposes of community care policy and practice and, as such, provided the context for a more detailed examination of the meanings they attached to the two sources of support.

Both respondent groups were asked to indicate whether family care or domiciliary care was more important to them in terms of nine types of care provision: help with housework; help with personal care; providing information (defined in terms of social security benefits); meeting other people (expressly non-relatives); providing emotional support; help with remaining at home; help with doing things for themselves; help with participating in leisure activities (excluding watching the television); and help with transport needs (defined in terms of getting to a doctor's or hospital appointment).

i: Elderly Participants

Table 9.1 reveals that elderly care receivers distinguished clearly between family care and domiciliary care. **Over three quarters (79%) stated that formal care was more important than family care for housework while just under three quarters (74%) stated that their families were more important than domiciliary workers in providing them with emotional support.** With regard to personal care, 53 per cent of care receivers indicated that family care was more important to them than formal care. By way of contrast however, the same proportion stated that formal care was more important than family care in terms of helping them participate in leisure activities and to meet other people. Finally, care receivers attached a broad equivalency to the importance of family and formal care in terms of maximising their self sufficiency and ability to remain at home.

Table 9.1: Elderly Participants' Assessments of the Relative Importance of Family and Formal Care

N=57 (%)

Function	**Family Care**	**Formal Care**	No Help Received
Housework	9 (16)	45 (79)	3 (5)
Personal Care	30 (53)	12 (21)	15 (26)
Information	19 (33)	25 (44)	13 (23)
Meeting Others	16 (28)	30 (53)	11 (19)
Emotional Support	42 (74)	4 (7)	11 (19)
Remain at Home	26 (46)	25 (44)	6 (10)
Self Sufficiency	19 (33)	24 (42)	14 (25)
Leisure Pursuits	10 (18)	30 (53)	17 (29)
Transport	27 (47)	22 (39)	8 (14)

Collectively, the results revealed that **elderly participants failed to attach any consistent superiority to family care over formal care.** Rather, they regarded families as more important for personal care needs and formal services as more important for instrumental assistance and sociability functions. It is important to

emphasise here that elderly participants were asked to compare the importance of family care and domiciliary services they received for each of the care functions and to make an absolute choice between them. This means that any distinctions they made between family care and formal care may have been exaggerated; indeed, their open-ended responses about the meanings they attached to family care and formal care contained far less rigid distinctions (see table 9.3 below). Nevertheless, when asked to make an absolute choice, the results suggested that care receivers experienced family care and formal care differently: domiciliary services were important because of their "tending"; and family care was important because of its "concern".

ii: Carers

The 18 carers were also asked about each of the nine care functions and to evaluate the importance of the care they provided in comparison with that provided by domiciliary services. Their responses are summarised in table 9.2 and reveal that **carers were almost unequivocal that the emotional support they provided their parents was more important than any provided by domiciliary workers.** The large majority of carers also indicated that they were the key carers who enabled their elderly parents to remain at home and who encouraged their parents to be as self-sufficient as possible. Similarly, carers attached more importance to the personal care they provided and also highlighted their major responsibility in meeting their parents' transport needs. Indeed, **the only area in which carers accorded more importance to formal services than to their own efforts was housework;** and even here, majority opinion was slim.

Carers thereby highlighted the primacy of their caregiving efforts in comparison with that provided by formal services:

> Ideally, families, without a shadow of a doubt, can give the best care to their elderly parents. Oh I know it's impossible because some families are moving about so, but it maintains the family structure...It's better that way. Carer 144

Table 9.2: Carers' Assessments of the Relative Importance of Family and Formal Care

N=18

Function	**Family Care**	**Formal Care**	Don't Know
Housework	8	10	-
Personal Care	13	3	2
Information	12	6	-
Meeting Others	10	8	-
Emotional Support	17	-	1
Remain at Home	14	3	1
Self Sufficiency	14	3	1
Leisure Pursuits	10	8	-
Transport	13	5	-

Of course, this conclusion is not without its exceptions. As the quotation below reveals, the primacy of family care depends upon carers' confidence in their relationships with their parents:

> I would say Dad benefits more from the services from (*the SWD*) because of the way I feel about him. It's about four years now since I've felt this way, *(anger and frustration)*. At first, I felt really guilty about it; now I don't. I do think if (*the SWD*) had been more forthcoming earlier, maybe it wouldn't have got to this stage...I give my Mum better care than (*the SWD*) because I care more for my Mum than they can.
> Carer 136

Carers' comparisons of family and formal care thereby differed in several respects from those of their elderly parents. First, they accorded more importance to the help they provided their parents with housework than did their elderly parents. Second, they considered the personal care they provided to be more important in absolute terms than did their parents. Third, whereas elderly parents were divided about the relative importance of filial support versus domiciliary services in terms of enabling them to remain at home and to be as self-sufficient as possible, their children considered their actions to be the key inputs here.

These comparisons suggest that carers and their elderly parents held different interpretations of the relative importance of filial and formal care. While carers appraised their caring efforts as consistently more important than those of domiciliary workers, their care recipient parents were more equivocal. Whether or not this is because parents under-valued the efforts of family and over-valued the efforts of domiciliary workers is examined below. What is certain at this point however, is that elderly respondents regarded themselves as more dependent upon the efforts of domiciliary workers and less dependent on the efforts of their adult children than their adult children thought was the case. This raises a series of questions about the accuracy of carer "mapping" studies which are based entirely upon the experiences and explanations of self-defined "primary" carers.

The Meaning of Family Care and Formal Care

A more open-ended approach was adopted to investigate the meanings that care receivers and carers attached to (as opposed to the relative import they assigned between) family and formal care. Specifically, both groups were asked to describe the best and worst aspects of the filial care they experienced. They were then asked to describe the best and worst aspects of the domiciliary services delivered. Respondents therefore considered family care and domiciliary care separately; a strategy which enabled them to attribute the same, as well as different, qualities and criticisms to both sources of support. As such, this simple question format provides a preliminary strategy for research which calls for the dismantlement of distinctions and boundaries between formal care and family care .

Responses were recorded verbatim and the coding frame allowed for two variables for each of the "best" and "worst" aspect questions.

b. The Best Features of Family Care

i: Elderly Participants

By way of preamble here, it is important to recall that 39 per cent of the elderly participants previously stated that they did not receive any help from any family member. This means that only 35 elderly participants were asked to describe "the best and worst aspects" of family care. Despite the acknowledged complexity which underpins the conceptualisation of care, elderly participants were able to isolate the aspects of care which meant the most to them. Collectively, they made reference to five "best" aspects of family care: the instrumental quality of care received; the emotional quality of care received; the combination of high quality task- and affection-based care received; the provision of gifts from their family; and visits and holidays at the home of their children. Table 9.3 below presents the relevant data. It also illustrates that 17 of the 35 care receivers, (49%), identified a second "best" aspect of family care.

Table 9.3: Elderly Participants: The Best Aspects of Family Care

Best Aspect	Aspect 1 n=35 (%)	Aspect 2 n=17	Total N=35 (%)
The Quality of Care - Task Based	12 (34)	8	20 (57)
The Quality of Care - Emotion Based	18 (51)	4	22 (63)
The Quality of Care - Both	3 (9)	-	3 (9)
Gifts from Children	1 (3)	3	4 (11)
Holidays at Children's Homes	1 (3)	2	3 (9)

A notable result presented above is the broad equivalency elderly participants attached to the instrumental and emotional importance of family care. Fifty seven per cent of the relevant care receivers nominated certain instrumental aspects of

family care as the most important feature of family care and 63 per cent identified the emotional aspects. In terms of the instrumental "best" aspects, elderly participants either mentioned specific tasks undertaken by their family carer(s) or the standard at which those tasks were completed:

> They (two daughters) do the shopping that I need; that's the most important. I don't feel I can go out; I'm afraid that I'll trip. They always see that I have a walk when the weather is good. Oh I definitely prefer the family to help me.
> Respondent 101

> The best thing is the dusting and cleaning: she (daughter) does it as I like it.
> Respondent 138

In terms of the "best" emotional aspects of family care identified by elderly participants, the outstanding feature was how a close underlying relationship affected the manner in which carers provided their support:

> The mere fact that they are helping me at all is a godsend. They do it with such delight that you don't feel obligated to them you know? It seems a pleasure for them to do it.
> Respondent 118

> They're *(three daughters)* most concerned, especially since the accident, *(car crash six weeks previously)*. I mean, I'm getting consideration from them that up to now I've never received. But now, when I gave up and cried...well they comforted me then.
> Respondent 140

> My sons are friends. I made them my friends when they were young. It's always been mateish between us you know: I've never used a heavy hand. It's their friendship that's most important.
> Respondent 141

These responses are evocative of the "tending" and "concern" dichotomy applied in the caregiving literature. Unprompted, elderly care receivers nominated the best aspects of family care in terms of labour and love. The major difference from the mainstream literature however was that their descriptions of this dichotomy were, for the most part, mutually exclusive. In other words, elderly respondents tended to identify either the instrumental rewards or the emotional benefits of family care.

For instance, of the 12 elderly participants who first highlighted the instrumental benefits of family care, only four also pointed towards the importance of the emotional aspects of family care. Of the 18 participants who identified the emotional underpinnings of family care as its best feature, only 7 proceeded to mention the instrumental benefits of family care.

Of course, the orthodoxy is that family care not only comprises instrumental assistance but has a vital added value embedded in emotion. Such a conceptualisation of family care however is founded upon the analysis of care provision and when the literature refers to the "meaning" of care it invariably refers to those meanings assigned by carers not care receivers. The data here reveal that care receivers separated the twin foundations of family care: the tending and the concern.

ii: Carers

As mentioned above, the 18 filial carers were also asked to describe the best aspects of caring for their elderly parents. Again, their responses were recorded verbatim. They first revealed that two of the 18 carers were unable to identify **any** best aspect of their filial caring activities. The quotation below bears poignant witness to the "costs" of caregiving discussed in detail above:

> Now I cannae say there's anything good about it, hen. The only thing I feel is at least I'm keeping Mum out of a place that would be full of people like Dad. You can't even say there's the advantage of having company in the house because I haven't. I stay in my bedroom because of my Dad. I hate him. I cannae bear to be in the same room as him.
> Carer 136

Sixteen of the 18 carers however had no such difficulty in identifying the positive aspects of caring for their elderly parents. Most notable, all of the relevant 16 carers highlighted certain personal benefits they derived from caring for their parents. Nine carers replied that caring for their parents stopped them from worrying:

> It's about trying to make her life a bit easier. She helps me as much as I help her, hen. I can say things to her that I wouldn't say to other folk. when you come to 87, you don't know how long she's left: you just want to know she's always alright. You wouldn't want to go round there and find her lying, not able to move. You'd feel terrible and then you'd think: "This wouldn't have happened if I'd been round yesterday.
> Carer 142

A further five carers indicated that they derived a sense of pride from helping their elderly parents:

> Well, I know two or three people with this senile dementia and you hear all sorts of awful things. And I look at my mother and she's always immaculate. She was a very good mother to us; she was always immaculate. And I want to keep her as long as I can; how she's accustomed to being.
> Carer 129

The remaining two carers said that helping their parents made them feel useful:

> It's just knowing you're able to help her: that you're not too far away.
> Carer 101

These responses highlight the tangible sense of benefit that carers derived from caring for their elderly parents. The very provision of care was its own reward and carers simply felt better as a result. Perhaps surprisingly, only half of the 16 carers pointed towards any relational benefits derived from caring for their elderly parents. These were expressed in three ways: love and affection; duty and expectation; reciprocity and repayment. For instance, three carers described the best aspect of helping their parents in terms of reciprocity:

> I suppose it's just knowing that I can do something to help her. She used to help me a lot when I worked full-time; she'd come down and do my ironing or the washing up and that; and she's help with the kids. I just feel I want to do something in reciprocation for all she's done.
> Carer 138

Another two respondents indicated that fulfilling their perceptions of filial duty was the best aspect of being their parent's carer:

> You've got to do it really: it's your mother and what else can you do? They brought us up. And that was the last thing Dad said: "Look after your mother". So I'm glad I can do it now.
> Carer 126

Two carers said that keeping their elderly parents out of residential care proved to be the most worthwhile aspect of being a carer:

> I think it's keeping her out of care. No matter how good they are, here she's got her own room and own fireplace so to speak. And I know how lonely these old people can be: it's out of sight out of mind. It's her keeping her home; that's the best thing.
> Carer 110

Finally, one carer indicated that being able to demonstrate their love for their parent in a practical way was the best aspect of their care provision:

> The best thing is, because I do it out of love of course, is that I'm allowed to do things and say things that nobody else would be able to do for her.
> Carer 100

By way of conclusion at this point, then, carers' descriptions of the "best thing" about caring for their elderly parents were inherently personal. With very few exceptions, providing care was its own reward. The relational benefits that care provision to elderly parents encouraged were less common. Conspicuous by its absence, not one carer specified any instrumental aspect of care in their descriptions of what was "best" about the care they provided. Their responses revealed that the best aspects about being their parents' carers were based upon emotions rather than actions. This contrasted starkly with the equivalent responses of the elderly parents: over half the elderly parents identified the quantity and quality of housework their children undertook on their behalf as amongst the best aspects of family care. Of course, the result that the most common "best aspect" of family care identified by elderly participants concerned the affectual benefits of filial support is evidence that they also understood and experienced the act of care from their children in affectual terms.

Possibly, the asymmetry between the accounts of elderly participants and their filial carers is not all that surprising. Without the care tasks provided by carers, the quality of life of the elderly respondents would, in all likelihood, have been impaired. The provision of a clean bed, groceries in the cupboard, a regular bath and clean clothes to wear make the difference between living at home in reasonable comfort and not being able to cope at home. By stressing the importance of the instrumental support their children provided, therefore, elderly respondents were illustrating their need for such chores to be undertaken before any quality of life could be attained.

c: The Worst Features of Family Care

i: Elderly Participants

The two respondent groups were also asked to describe the "worst" features of family care. In their responses, elderly participants pointed towards six characteristics: their dependency upon family carer(s); the sheer insufficiency of family care; tension in the relationship with their family carer(s); the over-provision of family care; the unreliability of family help; and the poor quality of family help. First and foremost however, the results reveal that **14 of the relevant 35 elderly respondents (40%) had no complaint whatsoever about the care they received from their family: very simply, there was no "worst" aspect.**

Although there was some evidence which suggested that the lack of complaint related to an unwillingness to criticise publicly their filial carers in any way, for the most part participants' inability to identify any "worst" aspects of filial care appeared to indicate that they were genuinely satisfied with the care they received:

> There's no worst thing. They're all good to me; to us both. Even the weans (*grandchildren*); they come. They always see that we're alright.
> Respondent 144

Table 9.4: Elderly Participants: The Worst Aspects of Family Care

Worst Aspect	Aspect 1 n=35 (%)	Aspect 2 n=11	Total N=35 (%)
No Reciprocity - give nothing in return	7 (20)	2	9 (26)
Not Enough Care Provided	5 (14)	-	5 ((14)
Poor Relationship with Carer	3 (9)	1	4 (11)
Too Much Care Provided	3 (9)	2	5 (14)
Care is Unreliable	-	2	2 (6)
Poor Quality	3 (9)	1	4 (11)
NO WORST ASPECT	14 (40)	-	14 (40)

The most common complaint voiced by elderly respondents however concerned their perceived dependency. Over a quarter (26%) stated that the care they received from their children evoked or exacerbated their feelings of dependency; most usually because of an inability to reciprocate. This result draws attention yet again to the overall reluctance that elderly respondents expressed in being the recipients of family care:

> Just needing the help; it's frustrating not being able to do anything you would like to do.
> Respondent 100

> I don't like having to be so dependent on him. But if I wasn't dependent on him, I'd have to get someone else to help me.
> Respondent 114

Table 9.4 also reveals that while only 14% of care receivers in receipt of family care complained that their families did not help them enough, an equal proportion stated that their families insisted on doing too much, a division reflected in the following quotations:

> They've all got front loaders and spin dryers, but there's not one of them that's said: "Mum let me take your washing." I always used to look after the bairns (*grandchildren*) so they could go out to work in the cafes and that, but they don't do anything now it's their turn. You just ask *(a friend)*, oh she's mad at the family. If they ever bothered to come they would see it; that I need help. I do feel bitter about it at times, but I would rather shut up than cause a row.
> Respondent 109

> She does too much for me. I always tell her, (*daughter*): "For goodness sake, you're tiring yourself out." But she still does it all; she can't just sit still and talk.
> Respondent 124

Finally, a very small number of care receivers (four), pointed to their relationship with their adult children as being the worst aspect of family care. Filial care constituted an a poor care option for these frail elderly people; family ties were fractured by filial assistance rather than cemented:

> The hard part is this, her Dad *(respondent's husband)* is getting aggressive with the Alzheimer's. I can take it, but she just goes into tears. He's like red rag to a bull; he throws back every little help she tries to give. He even told her to get out of the door the other week.
> Respondent 136

In such cases, the provision of domiciliary alternatives to family care are essential. The "caring relationship" places the bonds between elderly parents and their adult children under severe strain and can not possibly be of benefit to either party.

ii: Carers

By way of preamble to the discussion about carers' descriptions of the worst aspects of providing care to elderly parents, it is interesting first to compare the two respondent groups' failure to identify any negative effects of family care. Almost half of the elderly participants failed to identify any negative effects of family care. This compares to just two of the 18 carers:

> I can't think of anything here. I don't mind picking him up in the car or anything. He hasn't got any bad habits; he doesn't cause any arguments in the family. As I say, he's very easy.
> Carer 141

This is a notable difference between the two respondent groups: filial carers were more critical of the caring relationship in which they were engaged than were their care receiving elderly parents. It is possible of course, that the elderly participants were anxious to provide what they thought to be socially acceptable answers here and thus were reluctant to voice any criticisms of their filial carers[1]. Indeed, I uncovered at least one example where this was very obviously the case:

> I can't think of anything. I'm, how d'you say it...diplomatic. Aye, that's the word.
> Elderly Respondent 116

Social acceptability and protocol aside however, carers displayed higher levels of dissatisfaction with the caring relationship than did their elderly parents. Interestingly, though, there were also similarities between the responses provided here by elderly participants and their filial carers. Essentially, carers' descriptions of the worst features of family care, like those of their parents, revolved around personal and relational effects. In total, of the 16 carers who pointed towards some personal costs of care (defined as adverse effects upon their own lives as opposed to their relationships with their parents), the most common complaint involved the infringement of personal freedom which resulted from their actions as carer. Charts 9.1 and 9.2 below provide the necessary summary of carers' identification of the worst aspects of being their parents' main family carers and reveal that one third complained that looking after their parents limited their ability to do other things:

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[1] This is an acknowledged problem when interviewing elderly people as discussed earlier in chapter two.

It's the being tied down; that's what I find the most difficult. My husband supports me; he never complains about it. But it's like two or three weeks ago. It was the Sunday and I was getting ready to go out the door to the last tournament of the season (*golf*) when the phone went. It was the neighbour who looks after Mum when I'm not there saying: "Your Mum's gone missing". (*Mother wanders out of the house fairly regularly*). So I said: "OK, I'll come out". But my husband said: "You've got your own life. You've been looking forward to today. You go to your golf and I'll go out and look for her". Eventually he had to get hold of the police; he couldn't find her anywhere. You see, she normally has certain places she goes and you can find her quickly. But later that afternoon there was a phone call from the police to say that someone had found her.
Carer 129

Chart 9.1: Carers: The Worst Aspects of Family Care: PERSONAL

N=18

Linked to the lack of personal freedom, a further three carers complained about the amount of care they provided:

Sometimes you get fed up with the phone going. It's just that she always wants something and when she does want anything, she always wants it right away. You might be doing something yourself but you have to stop and go round right away.
Carer 126

In three cases, carers' sentiments about loss of freedom were particularly acute and had evoked a sense of isolation. These carers felt unsupported by other family members and formal services in caring for their parents; they simply had to cope as best they could on their own. The quotation selected below reveals the seriousness of a lack of support and how precarious the "caring" relationship becomes in its absence:

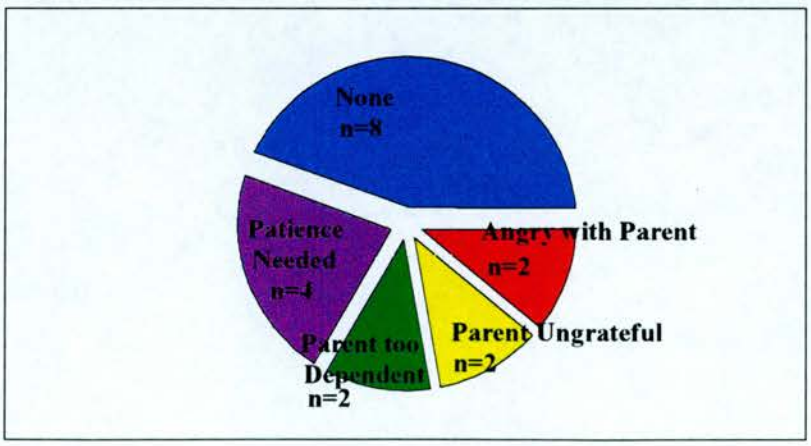
> I feel out on a limb. Basically, as things are, there's no one to back me; no one to lift a phone to, to say: "I am needing help here". Something is going to happen: it's such a volatile situation. I just feel that the social workers don't listen or understand what you say. When I tried to tell them how bad things were, she just kept saying: "We have a support group you know; you could come to that". But I don't need that...I have actually hit my father for God's sake and he's laid into me, that's how bad things are. I don't need a support group. I have one or two good friends I can talk to. I don't need to listen to everyone else's problems; I'm depressed enough with my own! Carer 136

By way of very great contrast, the final "worst" personal aspect that carers mentioned involved recognition of their parents' frailty and their inability to stem their parents' functional decline. These carers expressed nostalgia for the past, fear of the future as well as personal distress:

> The way she used to be; she was so active. It's seeing her sometimes. She always tries to be so independent and it upsets me sometimes. She still tries to make her own bed you know. That's the worse, seeing her now. Carer 110

Chart 9.2: Carers: The Worst Aspects of Family Care: RELATIONAL

N=18



From a personal perspective therefore, the worst aspects of caring for a parent involved the loss of freedom, the amount and constancy of care required, the lack of support from either formal or family sources and the distress that accompanied parental loss of functional independence. Notably, not one carer mentioned adverse effects upon either their employment or their health. In other words, the material consequences of care provision did not feature in the carers' personal lexicon: contrary to the emphases accorded in the literature, their "language of care" here described emotional responses and the infringement of personal autonomy.

Carers' responses were also coded for any comments they made about the adverse effects of caring upon their relationships with their parents. In total, ten carers referred to adverse relational effects; these are catalogued in chart 9.2 above. Carers' most common complaint here involved the difficulty carers had in keeping their patience with their elderly parents and carers' comments focused on the frustration they experienced in dealing with their parents:

> I think it's keeping your patience. She's always had a stubborn streak and I was brought up strict. But nowadays, respect doesn't come automatically, but it did when I was growing up. So when she's doing something that's dangerous or, you know, just plain stupid, you can't say: "For goodness sake mother, I've told you already, don't do it!". Rather, you have to count to ten and say: "Now then Mum, with all respect, we've discussed this. Now do please be careful and don't do that." It drives you mad! And sometimes all you want to do is yell.
> Carer 100

Two carers complained that their parents were overly dependent upon them and not in need of so much care:

> She won't help herself. that's it. And I get to do it all because she's so lazy. And she won't complain about the home helps. And she complains about swollen legs and that yet she won't take her tablets!
> Carer 142

Finally here, two carers thought that their parents were ungrateful for the assistance they provided:

> She's very ungrateful. She takes everything for granted. She'll tell you she's no ungrateful; that she appreciates what you do. But she's no (grateful at all).
> Carer 117

These "relational" results place the foundations and contours of intergenerational relations at the heart of the conceptual framework of filial care: carers were critical about their parents' attitudes and behaviours rather than the demands of disabilities and the tasks they were required to perform. As such, carers' comments contrasted with those of their parents whose major complaint was with their disability and consequential functional dependency. Whereas carers highlighted their parents' ill temper, lack of gratitude or refusal to strive towards maximum self sufficiency, their elderly parents' complaints centred around the extent of their care needs.

These disparities between carers' and care receivers' descriptions of the "worst" aspects of filial care brings back into focus the need for the conceptualisation of care to encompass the experiences and understandings of all parties involved. It is the caring "relationship" between adult children and their elderly parents which requires centre stage in the research arena. The types of tasks carers perform and the consequences of doing are important issues, but they should remain in the wings until the relations between the central characters are explored and the plot is unravelled.

d: The Best Features of Domiciliary Services

i: Elderly Participants

Elderly participants and their carers were also asked to identify the best features of domiciliary services delivered by the SWD. Specifically, elderly participants were asked:

> And what is the best thing about receiving services from (the SWD)?

Their responses were recorded verbatim and the coding frame allowed for two "best" aspects. More notably, table 9.5 illustrates that elderly participants drew a distinction between the functional and non-functional benefits of domiciliary care. Whereas 51 elderly participants pointed towards the functional benefits of domiciliary care, 36 also stressed the non-functional benefits of service receipt. In other words, **70 per cent of those elderly participants who identified functional benefits from domiciliary services also identified non-functional benefits.** This result is important: it repudiates any notion that the meaning of formal care as experienced by care receivers is grounded in instrumental support alone. Rather, service users also emphasised the non-instrumental benefits to service receipt:

> The best thing is, she (*the home help*) is able to do the things I'm not able to do. And she's company. She's a nice person; she has the same outlook on life as me. She's like a friend as well; when she comes here we have a talk and a cup of tea. You can share your thoughts with her; she's not a gossip. She's a nice person.
> Respondent 133

With regard to the functional benefits, there was a preponderance of references to the quality of work undertaken by home helps. **Forty five per cent (45%) of elderly participants mentioned the quality of the home help they received as being the "best" aspect of domiciliary care:**

> The home help is very good to me. I don't ask for more than her obligements (*sic)* like. I try to do what I can mysel' (*sic)*. But she tidied up the cupboard last time: I can't reach up to the shelves see; so she's very obliging.
> Respondent 135

The non-functional, "best", aspects of domiciliary care identified by elderly participants were the emotional, social, and financial benefits that accompanied service receipt. The relationship that care receivers enjoyed with their home help was of particular prominence here; 42% of relevant elderly participants indicated that the friendship and companionship they received from their home helps was the "best" aspect of their receipt of services from the SWD. The gender difference

here is very noticeable: only 2 of the relevant 12 male participants made any reference to the value they attached to their relationship with their home helps in comparison to more than half of the relevant 24 female participants. Female service users in particular developed valued and acknowledged friendships with home helps:

> You don't want to feel, but you do feel, friendless. People just don't want to know. So the home help, well their job is the important thing but she's friendly and that's the thing...the relationship you build up. For all they say, and I know some people moan, but they're (*home helps*) really good. They come to your house from the outside world and you build up a relationship. She's away for five weeks now, and I miss her like crazy.
> Respondent 128

Table 9.5: Elderly Participants: The Best Aspects of Domiciliary Services

Aspects **FUNCTIONAL:**	Male n=16 (%)	Female n=35 (%)	TOTAL N=51*
Quality of home help	6 (38)	17 (49)	23 (45)
Day Care/ Respite Care Attendance	4 (25)	4 (11)	8 (16)
Meals on Wheels	-	1 (3)	1 (2)
Transport	2 (13)	2 (6)	4 (8)
Home Care Management	-	3 (9)	3 (6)
Combination of above	4 (25)	8 (23)	12 (24)
NON FUNCTIONAL:	n=12 (%)	n=24 (%)	N=36**
Meeting Others	6	5 (21)	11 (31)
Relationship with Home Help	2	13 (54)	15 (42)
Eases Burden on Family Carer	1	4 (17)	5 (14)
Service is free of charge	3	2 (8)	4 (11)

* 6 missing cases here; 2 men and 4 women. ** Denotes the number of respondents who mentioned a non-functional response.

In similar vein, almost a third of relevant service users stated that the best non-functional aspect of formal services was that they fulfilled a variety of social and emotional needs:

> The Resource Centre; I think it's wonderful because it gets me out and I like it because they do quizzes and that. And then the physio came last week and they're starting exercises with me. They even want to get me working on a computer! And they asked me if I wanted to do any cooking even....It's unbelievable. And the girls up there; oh they're really marvellous.
> Respondent 125

> The community centre's good. It gets me out and you have a cup of tea twice a day as well as lunch. I've lots of friends there; they're mainly women of course, but that's OK. The welfare woman always says to me: "I'll have to watch you; you've a twinkle in your eye when you come here." You can have a joke there.
> Respondent 146 (male)

Fundamentally, these data demonstrate that elderly respondents valued domiciliary services because they fulfilled an array of instrumental, emotional and social functions. Domiciliary care meant far more than the completion of individual items of household management or personal care. Elderly participants, especially the women, placed a high value upon their relationships with individual formal carers (especially home helps), and upon the social life stimulated by their service use. Such data confirm therefore that formal care has far more in common with family care than has previously been supposed. Indeed, the very terms that elderly participants used in their assessments of the "best" aspects of formal services receipt were similar to those used in their descriptions of family care. Elderly people found it difficult to differentiate between the activities of formal carers and those of family members: they formed emotional attachments to their domiciliary helpers, and these paid workers (as represented in the accounts of the elderly respondents), appeared aware of, indeed catered to, the individual needs of their service users. Such conclusions add further weight to the argument that it is vital to dismantle the boundaries which separate family care from formal care in order to present a fuller picture of the dynamics of care.

ii: Carers

Research by Julia Twigg has highlighted the ambiguous status of family carers vis-à-vis formal services, an ambiguity which is addressed directly in the Carers (Recognition and Services) Act. Due for full implementation later this year, the Act places a duty upon local authorities to conduct a separate assessment of carers' needs in their development of care plans. The intention is the promotion of the "carer as client" relationship between family carers and local authorities. Part of the consumerist approach to the development of services is the inclusion of the carer perspective in studies which address service users' responses to services. Satisfaction surveys have acknowledged methodological flaws (Qureshi and Nocon, 1995) and so the focus here is again the language of care and carers' descriptions which elucidate upon the boundaries between the formal and the family divide.

The 18 carers were asked to identify the best aspects of the formal domiciliary services received by their elderly parents. Their responses were recorded verbatim and revealed three major categories of appreciation. First and foremost, carers appreciated the practical support that formal carers provided their parents. Second, they valued the emotional support their parents received from formal carers. Third, they pointed towards the personal support they received from formal carers.

By far the most common response was carers' appreciation of the practical tasks undertaken by formal carers. Almost three quarters of the carers defined the best aspects of domiciliary services in terms of instrumental support:

> Without them, I wouldn't be so well off; for the sake of the smooth running of the house. I'd have to find someone to bath my mother and I'd have to get someone to do the ironing. And the home help will do the hoovering occasionally and sometimes she'll even cook a meal.
> Carer 110

Inherent in this appreciation of the practical tasks undertaken by home helps was the realisation that it reduced their own necessary practical contributions.

Moreover, it increased their confidence that their parents were being "monitored"; someone was going in to see them even when they did not.

Over a third of carers (7) identified the emotional and social support provided to parents by formal workers or services as the most beneficial aspects of service delivery:

> I would say her day care really; otherwise she just vegetates sitting there in the chair all day. It gets her out and to meet a few people. It makes it easier for us too, *(respondent and her sister)*...it gives her an outside interest. Before she started going, we'd say to her: "Mum you should get friendly with a neighbour or someone". And she'd say: "I no need anyone; I've got youse *(sic)*".
> Carer 117

In other words, carers recognised the importance of their parents' relationships with both formal carers and other service users. They interpreted formal carers as their parents' "informal" friends and recognised that formal day care facilitated their parents' entry into social events. Significantly, the first quotation above also makes reference to a substitution effect between domiciliary services and family care: the carer's life was "easier" because the elderly parent was meeting other people via day care provision, meaning that the parent's reliance upon the carer and her sister was lower than it otherwise would have been.

By way of contrast, only three carers replied that the support they received on an emotional level from formal carers was amongst the best aspects of service receipt:

> I think the fact that you can pick up the phone and speak to someone who knows about Mum. You're not dealing with someone nameless.
> Carer 101

These data raise two issues about the relationship between family carers and formal services. First, the result that very few carers identified direct personal benefits from their parents' receipt of domiciliary care was belied by the fact that they consistently pointed towards indirect personal benefits. These included a reduction in the amount of practical help they were required to give and a

reduction in their anxiety levels brought about by a home help's regular attendance upon their parents. An apposite conclusion here is culled from research conducted by the University of York: the most important support formal services can offer carers is the provision of appropriate levels and quality of services (Twigg, Atkin and Perring, 1990). In other words, when formal services increase the physical, emotional and social well-being of service users, the stress and strain upon family carers is proportionally reduced.

The second point is that there was no evidence to suggest that carers had any personal relationships with their parents' domiciliary carers: they made no reference to any discussions which might have encouraged such relationships. This lack of dialogue has certain implications for the way in which family and formal care combined at the site of care delivery in the elderly participants' homes. At the very least, it suggests that the "sharing" of care responsibilities that occurred between family carers and formal carers was incidental rather than planned; haphazard rather than managed. Although carers' comments revealed that the practical components of their care were affected by the scope and levels of formal services provided, this occurred as a personal reaction to the services provided and not as any component of a deliberate and coherent "shared care" strategy.

e: The Worst Features of Domiciliary Services

i: Elderly Participants

Finally here, the two respondent groups were asked to describe the "worst" aspects of the domiciliary services delivered. Responses were again recorded verbatim and table 9.6 below highlights the results for the elderly participants. Its first noticeable feature is that almost a third (31%) of care receivers stated that there was no "worst aspect" about the domiciliary services they received:

> There's no worst thing. She's *(home help)* very nice; very civil. She enjoys a blether, but don't we all.
> Respondent 145

Table 9.6: Elderly Participants: The Worst Aspects of Domiciliary Services

Worst Aspect	Men n=15 (%)	Women n=39 (%)	TOTAL N=54* (%)
Service Cuts	3 (20)	5 (13)	8 (15)
Restrictions in Tasks Allowed	2	19 (49)	21 (39)
Holiday Cover	1	11 (28)	12 (22)
Poor Quality of Service	1	2 (5)	3 (6)
Changes in Personnel	4 (27)	3 (8)	7 (13)
Organisation of Home Care	5 (33)	4 (10)	9 (17)
Loss of independence	-	1	1 (2)
NO COMPLAINTS	6 (40)	14 (36)	17 (31)

The most common complaint voiced by elderly participants concerned the rules governing home help job descriptions. Over a third (39%) of participants complained that home helps were not allowed to undertake household chores they themselves were unable to do:

> It's just the home help thing I object to: no heavy work. The rules. To me, they've got a well paid, easy, job. They just come in, do the dusting and hoovering...I hear it all the time, the old folk are having to pay someone to come in on top of the home help....They've stopped doing a lot of things, so I'm paying a woman to do them. The home help isn't allowed to do anything heavy. But I mean, how can they expect old people to stand on a ladder and change a curtain or wash a window?
> Respondent 127

> Well they're no here long enough to do anything! Half an hour! They were just in and then away again. And then they cannae do the things you need when they do come. The head one down there (*home help organiser*) told me: "We depend on the likes of your family to do things like change your curtains." But what about the old folk with no family hen? Or family who no bother with them? It must be terrible for them; to see your own home go down like that. Because they (*home helps)* only really tidy up, hen; it's no big cleaning job they do.
> Respondent 144

This result suggests a discrepancy between current service planning priorities and the expressed needs and preferences of service users. Service users' statements confirm that they want, indeed need, a range of domestic services. Service delivery objectives however were intended to provide a "personal care" service which addressed the total needs of the person rather than their domestic requirements only. These objectives are laudable enough except that continued restraints on resources meant that the provision of domestic support had to be reduced despite the fact that it was exactly the service that elderly participants most desired.

The arrangements that covered home help provision during local holiday periods and a regular home help's annual leave were also a cause of complaint amongst elderly participants. The home help service provided during holiday periods was either limited to shopping, collection of pension and preparation of meals (in instances where the home help provided these services normally), or was not available at all if the home help's duties were ordinarily limited to domestic cleaning. The specific comments of elderly participants who were provided with holiday home help provision indicated that they experienced this holiday "cover" as chaotic and confused. They were not told who would come during their regular home help's holiday nor the day nor the time at which they could be expected to arrive. This meant that elderly participants were uncertain and uninformed as to what to expect. In total, over a fifth (22%) of elderly participants complained about the limitations applied to home help service during holiday periods:

> When the home help goes on holiday, I'll not get anybody. And I can't do it (the housework). Oh the holidays are a real problem. The one thing I do have bother with is if I need any money; there's no one to do it.
> Respondent 125

> It's this silly business during the home help's holidays: only getting someone in to do the shopping and never knowing when they're coming...and then when (*regular home help*) gets back, she's three weeks of cleaning to do!
> Respondent 135

What was interesting here was that although elderly participants complained about holiday periods and the chaotic delivery of home help service which characterised holiday periods, they failed to make any reference to times when their home helps were ill and unavailable for work. Whereas home helps would have had to prearrange their holidays and provided local management with notice of their intended absence for holiday purposes, no such forewarning would have been forthcoming in times of sickness. Why elderly participants should have been silent on this matter yet vociferous in their complaint about holiday cover was not investigated during the interviews and reasons can only be guessed at. One suggestion, however, is that the relationship they developed with their home helps encouraged them to be sympathetic to their home help's personal situation and therefore compliant with unco-ordinated service delivery during periods of illness and personal suffering. They may not have wished to complain about chaotic services during times of illness because their home help may have construed this as a complaint directed at themselves.

The way in which domiciliary care was managed was also a topic of complaint amongst elderly participants (17%):

> We don't see hide nor hair of the social work people. We've always to get in touch with them; it's difficult getting through...I suppose they've so many on their books they couldn't get around everybody.
> Respondent 108

Such complaints provide affirmation that elderly respondents had not participated in any care management activities or processes. Indeed, the care management axioms embedded in the 1993 community care changes (responsiveness to users, flexible use of resources, devolution of responsibility to front line staff and incorporating service user views in service planning and delivery) were conspicuous by their absence. Instead, users emphasised the remoteness of those responsible for planning and organising services. "Enabling" local authority goals were belied by anonymous bureaucratic practice.

Another 13% of elderly participants complained about service cuts:

> When I came out of hospital (*after a stroke*) I had a home help for an hour every day. Then they cut it back to half an hour. At the week-end it was three people in rotation for half an hour. And that's what I'm no very pleased about. The story going round is that they're cutting everyone. The supervisor came in to tell me. I cannae understand it; they cut it as you get older. And you're no getting any better, but they cut it.
> Respondent 102

The 1989 White Paper "Caring for People" made it clear that local authorities would be expected to develop "effective costing and charging procedures" and it is important to point out that domiciliary services were not means tested or charged for at the time of fieldwork. Nevertheless, elderly participants revealed that services were being reduced in a way which implied little recognition of ongoing care needs. Although the care needs of elderly people may stabilise, their chronic nature means that they usually increase. Reductions in service levels therefore suggest that any care gaps will be exacerbated, thereby reinforcing dependency upon the provision of support from family carers.

The noticeable characteristic about all these "worst" aspects of domiciliary services identified by elderly care receivers is that they were not directed at individual domiciliary workers. Care receivers were not criticising their individual home helps but the policies and management decisions which determined the scope and level of support they received from home helps. Elderly participants were most vociferous about the decisions which determined what home helps were allowed to do, the number of hours they were allocated and decisions taken to reduce those hours.

These "operational" complaints were in stark contrast to their complaints about family care. Fundamentally, family carers were criticised on personal grounds: they "couldn't be bothered", "didn't take enough care" or even "insisted on doing too much". Home helps on the other hand simply "weren't allowed". Unlike family carers, home helps bore no personal culpability for the inadequate support they provided. While elderly participants' compliments attributed similar qualities to

family care and formal care therefore (e.g., the emotional support that family and formal carers both provided), their complaints suggested that they nevertheless attached different sets of expectations to family and formal carers. Even though home helps might become friends, elderly participants never lost sight of the fact that they were "doing a job". While elderly participants came to enjoy similar benefits from formal care as from family care they nevertheless applied a conceptual distinction in terms of their expectations of the two sources which resulted in a disparity between the types of complaints they had of each.

ii: Carers

Carers were also asked to identify the "worst" aspects of domiciliary services received by their parents. Again their responses were recorded verbatim. Specific complaints concerned the levels of services allocated, the scope of services and gaining access to those services. First of all however, it is important to note that a third of carers had no specific complaint to make. For these carers, there were no "worst aspects" of domiciliary services:

> I don't think there's any worst thing. I know we can contact the social worker if we need anything. I think that (*the SWD*) is very good really...in comparison with the other places I've heard about.
> Carer 101

These carers were grateful for, and appreciative of, the domiciliary services their parents received. The remaining two thirds of carers however were more equivocal in their praise. One third of carers complained that the levels of services received by their parents was inadequate:

> We were really disappointed when they cut the home help in half (*sic*). Another thing is not only did they cut it in half but they changed it to a Monday which means he misses all the public holidays.
> Carer 141

A further third of carers stated that the scope of domiciliary services was the worst feature:

> It's the rules. It's like, if you need to change a net curtain they (*home helps*), can't do it. You would think that they should have a free rein to do what's actually needed. You can understand what they're aiming at: maybe it's more important to some folk that they go in to chat and that, or that they just do the day to day tidy up. But Mum doesn't come into that...Before her hip *(mother has problems with her hip and is awaiting a hip replacement operation),* she could do most chores hersel'. It's changing lightbulbs or curtains, things like that she needs.
> Carer 144

Finally, four carers complained about the difficulty they had encountered in gaining access to service managers and obtaining information about services available in the area:

> The fact that you're not told, by anybody, what is available to you in order to help you look after this relative.
> Carer 100

> The social workers, because they're never there and they don't listen to what you say to them. They make up their minds and you've to live with it.
> Carer 136

Of course, these complaints were highly reminiscent of those voiced by the elderly participants. Again, it was not so much the personalities, attitudes, competencies or even conscientiousness of individual domiciliary workers about which carers complained, but the management decisions which determined the level and scope of formal domiciliary assistance their parents received.

Conclusions

My review of the literature reveals that the conceptualisation of family care has overlooked the experiences and reactions of the receiver party of the caregiving relationship and concentrated almost entirely upon carers. This chapter has represented an attempt to redress this imbalance. I have argued that there are important reasons for incorporating the experiences of care receivers into a conceptual framework of family care: reasons which are based upon empirical necessity and analytical adequacy. First, I argued that the observed reluctance on the part of elderly participants to acknowledge and accept their care receiver status

may have resulted in the "profound ambivalence" often associated with the experiences of carers. The data presented in this chapter fails to confirm such ambivalence but does serve to highlight the contradictory emotions that the elderly participants experienced in their receipt of family care. The second reason I gave for incorporating the care receiver perspective into a conceptual framework of family care concerned the identification of interdependency, intergenerational reciprocity and exchange that may exist between a carer and care receiver. The data revealed that there was some evidence of interdependency: both carers and care receivers pointed towards the intrinsic rewards they reaped from receiving and giving support. Carers were quick to emphasise that they "received" as much support from their parents as they gave and that their parents' well-being conferred a positive personal effect upon themselves while their "dependent" parents emphasised the value they attached not only to what their children did, but also to the relationships they enjoyed with their children. In other words, there appeared to be some degree of symbiosis between the personal morale of filial carers and their aged parents. The third, and most important, reason offered for the incorporation of the care-receiver perspective concerned the identification of a research programme which accorded equal import to the respective needs of carers and care receivers. In particular, it is argued that care receivers may intervene in negative or positive ways to influence the outcomes of filial and formal care. The data produced by carers here confirmed the existence of both impacts and several carers provided particularly poignant descriptions of how their elderly parents affected the quality of care they provided.

The other major purpose of this chapter was to enter the debate about the necessity to develop a vocabulary of care which more accurately identified the similarities and differences between care receivers' and carers' experiences of family care and domiciliary services. First here, the question which forced the two respondent groups to make a choice between formal and family sources of care in their identification of the "most important" source of instrumental, social and emotional support revealed some fascinating results. For instance, care receivers were largely unequivocal that domiciliary care was more important to them than family care for

their instrumental needs. Their adult children on the other hand accorded their own instrumental efforts far more importance than their parents had done. Overall, the data produced by this question suggested that carers and care receivers held fundamentally different views about the relative importance of filial and formal care.

The other approach to revealing any similarities and differences between family and formal care concentrated upon the two respondent groups' descriptions of the best and worst features of family care and domiciliary services. Relevant responses to the best features of each source demonstrated that while 63 per cent of the 35 elderly respondents who received help from their families identified the emotional benefits they accrued from this family care, 70 per cent of all elderly participants pointed towards the emotional benefits they derived from domiciliary services. In particular, elderly participants valued the emotional attachments they developed with domiciliary workers who entered their homes. This provides clear evidence that there was a high degree of overlap between elderly participants' experiences of the positive aspects of family and formal care. As such, the data, limited as they are, add to the groundswell of opinion that research strategies need to abandon their exclusive treatment of formal and family care.

The differences identified by elderly respondents with respect to their experiences of family and formal care concerned their descriptions of the "worst" features of each source of support. Whereas they limited their criticisms of domiciliary services to operational matters such as service cuts and inflexibility during holiday periods, their criticisms of family care focused directly upon their family carers. Elderly participants "excused" any inadequacies of the support provided by home helps because of tightly circumscribed job descriptions. Adult children on the other hand were apportioned with personal culpability for any inadequate or inappropriate support. This suggests that although elderly care receivers attributed similar emotional benefits to family and formal care, the criticisms they applied to each source were based upon different sets of expectations. In the case of home helps, the elderly participants never lost sight of the fact that home helps were

doing a job that was defined and controlled by "someone else". They expected their adult children to have no such boundaries placed upon their caring contributions: they failed to justify any shortfall in their children's care in the way in which they justified those of their home helps.

10

FILIAL CARE FOR ELDERLY PEOPLE AND ITS LINKS WITH OFFICIAL WELFARE: CLOSING REMARKS

> There will always be unfinished business because change is a constant in addressing issues concerning parent care.
>
> Brody, 1990, p253

Introduction

The main message from the research is that the proper and necessary support of frail elderly people remains a key issue for social policy; one which is characterised by a vast literature and accentuated public profile. But while much research has been devoted to the provision of informal care to elderly people and to the use of formal services, and while such research has vital messages for those concerned to ensure the development of appropriate public policy, the absence of a family systems perspective, and failure to analyse the links between family and formal care at "ground level", mean that knowledge remains grounded in care provision rather than caring relationships and continues to promote a dichotomous conceptualisation of family and formal care which minimises opportunity for the exchange and dissemination of "good practice".

Discussion of Findings

The first half of the thesis was devoted to furthering understanding of the "dynamics" of filial care. The key interest was with elderly care-receivers and how they construed their children's provision of support or non-provision of support. In order to set the scene, however, the research first asked a series of questions commonly addressed within the care literature: questions pertaining to health status and related functional impairment. In doing so, many results mirrored those outlined elsewhere. Importantly for later examination of the meanings care receivers attached to filial and domiciliary care, the data reinforced the notion that, even in the face of multiple health problems, the ongoing abilities of elderly people remained more in evidence than any inabilities. This was because elderly participants refused to behave as passive recipients of care; they were tenacious in their efforts at self support and struggled hard against the limitations imposed by their chronic ailments. They also adapted their lifestyles and behaviours in the face of functional limitations. A notable example of this was the way in which some elderly people limited their geographical living space in order to maximise their potential for self-reliance. Very importantly, and central to any thesis of family care, the data also reinforced the feminine specificity of filial care and revealed that although sons assumed carer status, they generally did so in the absence of daughters. Recognition of the "patchwork quilt" of care and its central position in women's lives, of its connectedness with all aspects of their public and private relationships, is fundamental to any feminist perspective on care, and although this thesis has given more attention to the experiences of care-receivers, results have nevertheless evoked ongoing discussions about the concept of gender and its creation of socially constructed functional, structural and relational differences between men and women.

More originally however, the accounts of elderly participants have challenged the orthodoxy surrounding unshared care. When care-receivers admitted to any assistance from their families, they more often than not also identified a second family carer. The accounts of elderly participants made it very clear that when

two or more of their children were geographically proximate, their experiences of the organisation of filial care frequently involved all such children. That is not to say that care-receivers were not able to differentiate between different children in terms of the instrumental care loads they assumed, but rather that the provision of emotional support was also construed as "reliance". The accounts of carers here mirrored those of their elderly parents: even though the majority identified siblings as secondary carers, they too acknowledged the differential instrumental loads respectively carried.

The significant point here, however, is not that different adult children did different things, or even that instrumental support was unequally divided between them. Rather, the important point is that elderly parents and their nominated main filial carers were in agreement that other adult children were implicated in the elderly participants' care; that they too were assigned with carer status. Indeed, any "legitimacy" attached to a child's or sibling's refusal to participate in parental care was limited to geographical proximity and, to a lesser extent, low levels of affect between the two parties. In this way therefore, descriptions of filial care as "normative" are highly appropriate.

As well as agreement between care-receivers and their adult children, results also revealed several disjunctures between their respective accounts. For instance, carers and care-receivers had peculiar understanding of what was, and what was not, "care" as revealed by practical support. The large majority of carers described how they had been "caring" for their parents prior to the introduction of domiciliary services while their parents often provided accounts which stressed their self-care activities and capabilities and the absence of filial support prior to such introduction. Whereas carers' experiences presented a score in which filial care provided the prelude to domiciliary care, care-receivers' acknowledgement of filial care was often coincidental with the introduction of formal services. Such results point towards a fundamental asymmetry between the experiences and understandings of carers and care-receivers; an asymmetry that requires further research.

The other principle theme that was explored in this thesis concerned the links between filial care and official welfare in the form of domiciliary care. As stated in *Caring for People,* four strategic axioms underpin community care policy: flexible services which are sensitive to the needs of care-receivers and carers; the promotion of service user choice; minimalist intervention; and a concentration of resources upon those with greatest needs. Such intentions are operationally pursued via care management, detailed assessment and a functional division of the purchaser/provider roles. Strategy and operations amalgamate into a "quasi-market" model of community care arrangements. Within available resources, policy and practice purportedly combine to meet the expressed needs and preferences of "service users" via their participation, service procurement and provision. The fundamental flaw in this strategy is that reduced public expenditures means that any concerns with equity, choice and participation are compromised by the urgent need to increase "efficiency" and refine allocation.

It is this tension which, of course, lies at the heart of discussions about the "rhetoric" of community care. In the same way that a range of domiciliary services does not equate to their actual utilisation, it is important to stress that laudable strategic intent does not deliver equitable operational practice unless underpinned by adequate resources and political will. Like many an "inflated" market therefore, the success of the community care quasi-market depends, in part at least, upon "consumer confidence": service user involvement in care management and service planning is one way in which such confidence may be bolstered. Care-receivers and carers should be involved in the assessment of their needs and decisions about their service requirements and care plans and this involvement should foster their empowerment.

The results of this research revealed that as far as service user involvement and participation were concerned, the reality of community care policy fell far short of its rhetoric. There was virtually no evidence of care-receivers or carers being involved with any processes or decisions pertaining to the assessment of their needs or allocation of services. In contrast to ideas about family carers behaving as

"quasi- care managers", very few carers in this study either accessed domiciliary services on their parents' behalf or attempted to influence those services via mediation or advocacy . Rather, health professionals were largely responsible for facilitating elderly participants' entry into the formal domiciliary care system while domiciliary carers, if anyone, provided the functions of mediation and advocacy. For the mainpart, services were allocated without carers or care-receivers being consulted, without them having any sense of user accountability or rationalisation of need and without any experience of user participation or choice.

Furthermore, the "consumer rights" of elderly service users and their carers were contravened by management decisions to withdraw services without first providing them with means of complaint or appeal, and to change the content of services without first promoting a process of consumer consultation. For instance, neither elderly care-receivers nor carers wished for fundamental change to the content of home help service. They wanted home helps to continue to provide instrumentally based, practical support; indeed they described how their care needs were exacerbated by such withdrawal. Despite their protest however, the home help service continued along its inexorable path towards a model of service provision which devalued those tasks care-receivers and carers prized the most. In other words, the force for the professional, specialised role of the home help (one which is based upon specific tasks, technical knowledge and structured response), is contrary to the expressed preferences of elderly care-receivers who want their home helps to be flexible and responsive to their requests.

A particular paradox highlighted by the study was that the remoteness and unbalanced relationship struck between elderly care receivers and domiciliary care management was belied by the friendship and close emotional attachment they often developed with front-line domiciliary workers, especially home helps. And even though care-receivers and carers complained about the inadequacy of the "tending" allowed by domiciliary service rules, they nevertheless interpreted the formal provision of instrumental support as demonstration of an emotional

attachment between themselves and individual paid carers. Indeed, although aware of its commodified status, the "value" care receivers attached to domiciliary care was incumbent upon emotionality. The relationships elderly care-receivers formed with home helps and day care staff defies the argument that formal care can only be understood in material terms.

Despite apparent attempts by service management to delimit the boundaries of relationships between domiciliary carers and service users (as witnessed by strict rulings over permissible tasks and regular reappointment of individual home helps), these relationships were infused with a vitality based upon affect. In other words, care-receivers' perceptions of, and significance accorded to, their exchanges with domiciliary workers spread far beyond simple functional limits and mirrored the intimacy and reciprocity attributed to effective family care. The relationship that developed between elderly service users and the paid carers who entered their homes was one of beneficence in which the attention domiciliary carers devoted to the social and emotional needs of service users were as much valued as any instrumental support they provided.

Relationships between filial carers and domiciliary workers were far more functional. Carers rarely developed the close emotional bonds with domiciliary workers enjoyed by their parents. While there was evidence to suggest that service provision relieved carers from responsibility for certain instrumental tasks, domiciliary services nevertheless did little to relieve carers' subjective sense of "burden". The weekly visit from the home help might have relieved them of the necessity to clean or shop, but it was irrelevant to their feelings of responsibility toward their parents and the strain this engendered. Of course, many researchers acknowledge that the union between caring "for" and caring "about" someone intensifies the stress experienced by carers. Nevertheless, this result makes for apposite reference to the now enforceable Carers' Act which imposes a duty upon local authorities to consider separately the needs of carers in assessments for domiciliary care. Evaluation of the Act will no doubt stimulate an important body of research into the effects of the systematic intervention of domiciliary services

into family caregiving., and such evaluation will need to look at the social and emotional support provided to carers by formal services as well as the alleviation of practical, instrumental tasks.

It has been said before, of course, that as far as family care is concerned, "policy is personal" and, indeed, the care literature illustrates in vivid detail how family care cuts across the personal and political boundaries of public and private lives, employment and family, action and emotion. But there remains a host of vital topics about which the care literature remains equivocal and this research has addressed two such issues in particular: an analysis of filial care which includes a care recipient perspective, and identification of the links that exist between filial care and official welfare. I hope it has made a useful contribution to the "unfinished business".

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APPENDIX 1

LETTER REQUESTING PARTICIPATION

HEADED PAPER

Date

Dear

I am writing to you about a study that is currently being conducted in (*the Region*). The study is being undertaken by Carol Tozer, of the University of Edinburgh, and looks at how elderly people manage at home with any help from their families and services provided by the (*Region's*) Social Work Department. The study will provide important information about the needs and views of elderly people and their family carers.

You name has been randomly selected and I am hoping that you will agree to take part in the study. It will involve an interview in your home and will take about forty five minutes. All of the information you provide will be treated with the strictest confidence and it will not be possible to identify you in person in the final report.

Please complete the attached form and return it to me using the pre-paid envelope provided. If you agree to take part in the study, Carol will be in touch with you during the next three weeks to arrange a time for an interview with you.

I look forward to hearing from you,

Yours sincerely.

(Name)
Research Officer.

APPENDIX 2: THE CARE RECEIVER INTERVIEW SCHEDULE

Thank you very much for agreeing to take part in this research. The questions I will ask concern your need for help around the home, and the sorts of help you receive from your family and others. All of the information you give me today will be treated as confidential, and when I come to write my report no-one will be able to identify you personally.

PERSONAL AND HOUSEHOLD DETAILS

1. Sex of respondent.

MALE	1
FEMALE	2

2. How old are you? (To nearest year)

3. Can I just check, are you married, never been married, widowed, divorced, or separated? (Circle)

MARRIED	1
NEVER MARRIED	2
WIDOWED	3
DIVORCED	4
SEPARATED	5

4. Now I need some information about your living arrangements. Do you live here alone, or with someone else? (Circle)

LIVE ALONE	1
LIVE WITH SOMEONE	2

(If 1 go to 5; if 2 ask 4a)

4a. Can I just check, is that just your husband/wife, or does anyone else live here too?

LIVES WITH SPOUSE ONLY	1
LIVES WITH OTHERS	2

(If SPOUSE ONLY go to 5)

4b. So not counting your husband/wife, how many other people live here with you?
(Enter number)

4c. Could you tell me who these people are? (Enter number in table below according to relationship)

4d. What is their relationship to you?
(Enter in table below and note sex of oldest in sibling, child, and friend categories)

4e. How old are they?
(Enter in Table below for oldest in sibling, child and friend categories)

4f. And do they work at all?
(Enter in table below for oldest in sibling, child and friend categories)

Rel to CR	Number	Sex (Oldest)	Age (Oldest)	Employment Oldest
Child				
Sibling				
Friend				
Grandchild				

Sex

1. Male
2. Female

Employment

1. Yes - F/Time
2. Yes - P/Time
3. No

Ages of Others

1. 20-39 2. 40-54 3. 55-59 4. 60-64 5. 65-69
6. 70-79 7. 80-89 8. 90 and over

4f. Can I just check, how long have you been living here?

Less than 6 months	1
6 months to 1 year	2
1 year to 5 years	3
5 years or more	4

4g. And do you rent/own this household, or does it belong to/is it rented by, someone else?

Owned/Rented by Resp/Spouse	1
Owned/Rented by Someone Else	2

(Check if respondent is living with anyone other than spouse. If so, ask 4h, otherwise go to

4h. And can you tell me why you and your ..... decided to live together? (Circle)

RESPONDENT'S CARE NEEDS 1
OTHER 2
(Record verbatim)

FAMILY NETWORK

So far, I have asked you about your living arrangements and the people who might live with you. Now I would like to move on to finding out more about your family generally.

5. Do you have any children?

YES 1
NO 2

(If No go to 8)

6a. How many children do you have?
(Record Number)

6b. Can you tell me a bit about them. Starting with the oldest, can you tell me: their sex and age; whether they have any children; the age of their youngest child; whether or not they are married; whether or not they work; and how far away they live from you

Sex	Age	No. Kids	Age Youngest	Married	Work	Time Away

Sex
1. Male
2. Female

Married
1. Yes
2. No

Work
1. Yes - F/Time 3. No - Retired
2. Yes - P/Time 4. No - other

Age of Children
1. under 40 2. 40-54 3. 55-59 4. 60-64 5. 65-69
6. 70-79 7. 80-89 8. 90 and over

Age of Youngest Grandchild
1. Under 5 2. 5 to 16 3. 17-25 4. over 25

Distance Away
1. Same H/hold 2. less than 10 mins. 3. 11-30 mins.
4. 31-60 mins 5. More than an hour-less than a day 6. Day +

7. Now I want to find out how often you see or stay in contact with each of your children. Again starting with the oldest, how often do you: have face to face contact; telephone one another; and stay in touch by mail.

Child (sex)	Face to face	Telephone	Write

Sex
1. Male
2. Female

Face to Face Contact/Telephone
1 Less than monthly
2. About once a month
3. A few times every month
4 Weekly
5 Daily
6. Same H/Hold

Mail
1. Never
2. Birthdays and occasions only
3. Few times a year
4. Monthly
5. More than monthly
6. Same H/Hold

8. Do you have any brothers or sisters?
YES 1
NO 2
(if No, go to 9)

8a. How many?
(Record Details)

9. Do you have any other relatives in addition to those we have already spoken about?
YES 1
NO 2
(If No go to 10)

9a. Can you tell me who they are. (Record number and identity)

HEALTH

Now I'd like to move on to finding out a bit about your state of health, and whether it affects you in terms of what you can or cannot do.

10. Do you have any long-standing illness or disability that either has troubled you over a long period of time, or is likely to affect you over a period of time?

Yes.....1
No.....2 (go to 12)

11a. (If Yes) Could you describe it for me? (Record verbatim)

11b. Observed physical difficulties:

	Yes	No
Hearing impairment	1	0
Visual Impairment	1	0
Wheelchair	1	0
Uses Cane, Crutches, Walker	1	0
Walking Difficulties	1	0
Crippled Hands or Legs	1	0
Coughs continually	1	0
Shortness of Breath	1	0
Skin Problems	1	0
Speech problems (not language)	1	0
Other physical disabilities (specify)	1	0

FUNCTIONAL ABILITIES AND HELP RECEIVED

12. Now I want to find out a bit about what you can and cannot do for yourself. I am going to read out a list of tasks that people need to do every day, or at least fairly regularly, and I'd like you to tell me whether you can do this task on your own with no difficulty, whether you can do it, but with some difficulty, or whether you are completely unable to do it. I'll also check whether you get any help with each of these tasks.

Task	Unable	Difficult	Able
Bath/Shower	2	1	0
Getting in/out bed	2	1	0
Going to toilet	2	1	0
Getting around inside	2	1	0
Walking to bottom of road	2	1	0
Prepare main meal and clear up	2	1	0
Shopping (Groceries)	2	1	0
Paying Bill/handling money	2	1	0
Using telephone	2	1	0
Light Housework	2	1	0
Heavy Housework	2	1	0
Light Laundry	2	1	0
Heavy laundry	2	1	0

13. Next, I want to find out who helps you with each of the tasks we've talked about, and whether the help you receive is enough to meet your needs.

Task	ID Main helper	ID other help	Help enough?
Bath/Shower			
Getting in/out bed			
Going to toilet			
Getting around inside			
Walking to bottom of road			

Task	ID Main helper	ID other help	Help enough?
Prepare main meal and clear up			
Shopping (Groceries)			
Paying Bill/handling money			
Using telephone			
Light Housework			
Heavy Housework			
Light Laundry			
Heavy laundry			

ID of Main Carer
1. Spouse
2. Daughter/in law
3. Son/in law
4. Other relative
5. Friend/neighbour
6. Home Help etc.
0. No help received

ID Of Other Help
1. Spouse
2. Daughter/in law
3. Son/in law
4. Other relative
5. Friend/Neighbour
6. Home Help etc.
0. No help received

Help Enough?
1. Yes
2. No
0. No help received

FILIAL CARE RECEIVED

14. Thinking now about all the help you receive from members of your family, who would you say you rely upon the **most**?

Spouse.....1
Daughter/in law.....2
Son/in law.....3
Other relative.....4

No family member.....5
(Record comments verbatim)

Can you give me her/his name and address and telephone number

14a. Again thinking about any help you receive from your family, who do you **next** most rely upon after your .....(see relative noted above)?

Spouse.....1
Daughter/-in law.....2
Son/in law.....3
Other relative.....4

No (other) family member.....5
(Record comments verbatim)

15. And is there anyone **outside** your family who provides you with even more help than your ..... (see 1st relative noted above)?

Yes.....1
No.....2

16. Who is this person outside your family who provides you with more help than members of your family? (Describe fully)

17. Is there anyone in your family who would **like** to help you more than they do, but are unable to for any reason?

Yes.....1
No.....2

(If YES ask 17a. If NO go to 18)
17a. Can you tell me who this is?
(Code up to 2 people)

Person 1.....Spouse.....1
Daughter/in law.....2
Son/in law.....3
Other relative.....4
(specify)

Person 2.....Spouse.....1
Daughter/in law.....2
Son/in law.....3
Other relative.....4
(specify)

17b. And why can't they help you more than they do?

Person 1.....Employment.....1
Own family to care for.....2
Ill Health.....3
Too far away.....4
Other (specify)
Person 2.....Employment.....1
Own family to care for.....2
Ill Health.....3
Too far away.....4
Other.....5
(Record verbatim)

18. Again thinking about members of your family, is there anyone who you think <u>should</u> be helping you more but who isn't?
Yes.....1
No.....2

(If YES ask 18a. If NO go to 19)

18a. Again, can you tell me who this is.
(Code up to 2 people)
Person 1.....Spouse.....1
Daughter/in law.....2
Son/in law.....3
Other relative.....4
(specify)

Person 2.....Spouse.....1
Daughter/in law.....2
Son/in law.....3
Other relative.....4
(specify)

(Record verbatim)

19.. And do you ever feel that any member(s) of your family insists on doing too much for you?
Yes.....1
No.....2

(If YES ask 19a. If NO go to 20)

19a. Who is this? (code up to 2)
Person 1..... Spouse.....1
Daughter/in law.....2
Son/in law.....3
Other relative.....4
(specify)

Person2.....Spouse.....1
Daughter/in law.....2
Son/in law.....3
Other relative.....4
(specify)
(Record verbatim)

20. And what about the amount of help you receive altogether from your family. Is it:

Too much.....1
About right.....2
Too Little.....3

(Record verbatim)

21. In the past year have you **given** any financial assistance to any member of your family, (apart from your (spouse) that is)?

No, not at all.....1
Infrequently.....2
Regularly, I partially support them....3
Regularly, they get most of their support from me.....4

(If YES ABOVE, probe for identity and motives)

22. In the past year have you **received** any financial assistance from any member of
your family (apart from your spouse that is)?

No, not at all.....1
Infrequently.....2
Regularly, they partially support me.....3
Regularly, they get most of their support from me.....4

(If yes above, probe for identity of donor and circumstances)

23. Do you ever help any of your children in terms of any housework, baby-sitting, or any other chores or errands?

Never.....1
Very Occasionally.....2
Fairly Regularly.....3
Often.....4

24. And did you ever do this in the past for any of your children?

Never.....1
Very Occasionally.....2
Fairly Regularly.....3
Often.....4

25. Next I want you to think about how well you get on with each of your children, and their spouses. Starting with your oldest child, I would like you to indicate between a score of 1 to 4, how strongly you agree with each of the following statements.

Statement	c1	c2	c3	c4
How often they make you feel loved and cared for				
How much they are willing to listen about your worries				
How critical they are of what you do				
How often they make too many demands on you				

Scale: 1 - not at all
2 - a little
3 - quite a bit
4 - a great deal

24. Now I'd like to find out a bit about your attitudes towards family life. I am going to read out a list of statements, and I want you to tell me whether you agree or disagree with each one.

1 = Agree; 2 = Disagree; 3 = Don't Know

a. taking care of elderly parents is as much a son's responsibility as a daughters.

b. One of the good things about having your family help you is you get the chance to help them back.

c. Friends and neighbour can't be expected to help older people the way their children do.
d. Adult sons should be expected to do the same things as adult daughters for their elderly parents.

e. I don't like to get help from other people unless I can help them too.

f. Nowadays, adult children do not take as much care of their elderly parents as they did in the past.

g. Sons make valuable, dependable helpers when it comes to doing things for their elderly parents.

h. People grow wiser with the coming of old age.

i. When most people need assistance, they are as satisfied receiving it from a son as the are from a daughter.

j.Most older people wish they didn't need as much help as they do.

k. People who have helped their children financially deserve more help from them than parents who have not.

l. Most older people dislike the behaviour of the younger generation.

SECTION SIX: FORMAL SERVICES

Next I want to move on to the how and why you started to receive services at home from the Social Work Department.

25. First of all, who approached the Social Work Department for the help that you now receive from them?

Self referral.....1
Spouse.....2
Daughter/in law.....3
Son/in law.....4
Other Relative.....5
Neighbour/friend....6
GP.....7
Hospital S Work.....8
Other.....9

(If coded 2, 3, 4 or 5 above, check if this is the main carer).

Main carer? Yes.....1
No.....2

26. Can you tell me why you/your ..... approached the Social Work Department for help?
(Record verbatim).

27. Can I just check, when did you first start to receive help from the Social Work Department?
(Enter number of months)

28. And what sort of services do you receive, and how much do you get?

Service	Received?	Frequency	Hours
Home help			
Day care			
Hospital day care			
Respite Care			

Received
1. Yes
2. No

Frequency
1. More than once daily
2. Daily
3. Monday to Friday
4. Week-ends
5. 2-3 Times per week
6. Weekly
7. Less than weekly
8. Less than monthly

Hours
1. Less than one hour per week
2. One to five hours per week
3. Over five hours, up to ten hours per week
4. 10-19 hours week
5. 20-29 hours week
6. 30 hours and more

Service	Received?	Frequency
Meals on wheels		
Transport		
Foster carer placement		

Received
1. Yes
2. No

Frequency
1. More than once daily
2. Daily
3. Monday to Friday
4. Week-ends
5. Two or three times per week
6. Weekly
7. Less than weekly
8. Less than monthly

Service	Received?
Community Alarm	
Adaptation to home	
Free TV licence	
Wheelchair	
Chiropodist	
Evening tuck in	
Other (specify)	

29. Thinking of all these services that you receive from the SWD, do you think you receive too much, too little or about the right amount of each service?

Service	Too Much	Too Little	About Right
Home Help			
District Nurse			
Specialist Therapy			
Day Care			

Service	Too Much	Too Little	About Right
Hospital Day Care			
Meals on Wheels			
Transport			
Respite Care			
Foster Care			
Auxiliary Nurse			
Incontinence Service			

(Probe for comments)

30. Can I just check, do you feel that you need any other service or help from the SWD, I mean in addition to those you already receive?

Yes.....1
No.....2

(If YES ask 30a. If NO ask 31)

30a. Can you tell me what these additional services are?
(Record Fully)

31. Next, I want to check what happened before you started to receive these services from the SWD. Thinking first about your housework, who used to do that before you started to receive a home help?
(Record verbatim)

(If FAMILY CARER, check if this is the same person named as main carer.

32. So when the home help first started to help you with your housework, what happened in terms of any family help you received then?
(Probe and record verbatim)

33. And what about before you started to go to day care/lunch clubs? Did your ..... (main carer) come around to see you more during the day before you started going out to day care/lunch clubs?

Yes.....1
No.....2
Resp lived with carer.....3
No day care etc.....0

(Record fully)

34. What about any other members of your family, did any of them used to come round during the day to see you before you started to go to day care/ lunch club?

Yes.....1
No.....2
No day care etc.....3

(If YES ask 34a. If NO etc. go to 35)

35. So would you say that going to day care has increased, decreased, or not affected how much you see these members of your family?

Increased.....1
Decreased.....2
Not Affected.....3
No day care etc.....0

(Record comments)

36. And who used to cook your main meal before you started to receive meals on wheels?

(Record fully)

(If FAMILY CARER, check if this is the same person named as main carer)

37. So can I just check, what happens at week-ends. Who cooks your main meals then?

(Record fully)

38. What about the transport you use which is run by the SWD. Why did you start to use it?

To go to Day Care etc only.....1
1 above plus other uses.....2
Don't use dial a ride etc.....0

39. And does any member of your family ever help you with your transport needs, for instance to day care/lunch club etc?

Yes.....1
No.....2
Don't go to day care etc.....0

40. What about getting to any appointment, or social event, does any member of your family help you with transport on these sorts of occasions?

Yes.....1
No.....2

41. Now I want to move on to when you go into a residential/nursing home for respite care when your ..... (main carer) either needs a break or goes on holiday. First of all, what used to happen when your .... (main carer) went away, I mean before you started to go into the residential/nursing home? Did you:

Stay at home by self/with spouse
- no problems.....1
Family member looked after resp.....2
(specify)
Friend/neighbour looked after resp.....3
Temporary domiciliary support provided..4
Other (specify)
Never uses respite care facility.....0

42. And do you make use of this respite care facility everytime your ..... (main carer) needs a break/goes away?

Yes.....1
No.....2

(If NO ask 42a. Otherwise go to 43)

42a. So what happens when you don't go into the respite care facility.
(probe)

43. Now I want you to compare how important the care you receive from your family is with the service you receive from the SWD. First of all, what are the **best** aspects of having your family help care for you?
(Record fully)

And what are the **worst**?
(Record fully)

44. And what about the services from the SWD? What are the **best** aspects of the services you receive from the SWD?
(Record fully)

45. And what are the **worst**?
(record fully)

46. And who is **most** important in helping you with the following things, your family or the services from the SWD?

Task	Family Care	Formal care
Help with housework		
Help with personal care		
Providing information		
Meeting other people		
Providing emotional support		
Helping you to live in your own home		
Helping you to do things for yourself		
Helping you to join in leisure activities		
Helping you to get to appointments		

ATTITUDES TO FORMAL SERVICES

47. This final section of questions concerns your opinions about the service provided by the SWD. I am going to read out a series of statements and I want you to tell me whether you agree or disagree with each.

People outside my family think less of me because I use services from the SWD

My family thinks less of me because I use services from the SWD.

My family are unhappy about my using services from the SWD.

My family supports my use of services from the SWD

People employed by the SWD can take as good care of me as my family.

I am fearful of having people from the SWD looking after me.

People from the SWD follow my directions in taking care of me.

It is hard to trust anyone from the SWD to take care of me.

People from the SWD are better at caring for me than my family

The SWD might have better ideas about caring for me than my family.

I would rather use services from the SWD than ask for help from my family.

I would rather ask for help from the SWD than ask for help from friends.

I would rather ask my family for help than ask the SWD.

I would rather ask my friends for help than use services from the SWD.

My family is proud to be able to care for me with little help from the SWD.

I believe that families should care for their own and not ask for outside help.

My family thinks that they should care for me without help from the SWD.

My family feels good about using the SWD to help take care of me.

It is not the government's responsibility to take care of me.

I would use more services from the SWD if they were available.

The government should support more social services to help families care for elderly relatives.

APPENDIX 3: CARER INTERVIEW SCHEDULE

Section A: Personal and Household Details

1. Sex of carer
2. Date of Birth
3. Marital Status (married; never married; widowed; divorced; separated)
4. Relationship to elderly parent (Daughter; daughter-in-law; son; son-in-law). Also ascertain if other parent is alive.
5. Employment Status (full-time; part-time; unemployed - looking for work; homemaker; retired)
6. Living Arrangements - a. whether lives with elderly parent (Yes; No)
b. identity of other household members (spouse; child(ren) other relative(s); non-relative(s).
7. If living with parent, length of time spent living together, reason for living together (ad verbatim response), and identity of party which moved (parent into child's home; vice versa; or both moved)

Section B: Family Characteristics and Associational Proximity

1. Personal Details of Spouse, if married: age, employment status, and number of years married. Ascertain whether or not this is the only marriage. Obtain details about length of previous marriages

2. Number, gender, and age of children/step-children. Ascertain whether or not each child is living with the respondent (full-time students away at college/university, classify as not living at home)

3. Gender, age, marital status and employment status of each siblings (including their spouses). Also, number, gender, and age of siblings' children.

4. Distance between respondent and each sibling in terms of: 1. same household; 2. less than 10 minutes away; 3. 11-30 minutes; 4. 31 to 60 minutes; 5. more than an hour but less than a day away; 6. more than a day's journey.

5. When living separately, frequency of face-to-face contact between respondent and siblings (more than once daily, daily, 3/4 times per week, weekly, less than weekly)

6. When living separately, frequency of telephone contact (same scoring as above)

7. When living separately, frequency of receiving mail (to be coded into times per year).

8. How close is the relationship between respondent and each sibling (Not at all close=1; Extremely close=10)

9. Distance between each sibling and aged parent in terms of: 1. same household; 2. less than 10 minutes away; 3. 11-30 minutes; 4. 31 to 60 minutes away; 5. more than an hour but less than a day away; 6. more than a day's journey.

Section C: Relations with Aged Parent

1. Affectual Solidarity
Your (elderly parent) understands; trusts you; is fair to you; respects you; has affection for you; you understand her; trust her; are fair to her; respect her; have affection for her; how good is communication between the two of you; generally how well do you get on? etc. (Scale 1 to 10)

2. Functional Solidarity i.e.. defined in terms of gifts, services and money.

a. In the past year have you given your ...(parent) any financial assistance?
b. In the past year have you received any financial assistance from your ...(parent)?
(Prompt: No, not at all; infrequently; Regularly - I partially support them; Regularly - they get most of their support from me)

c. How often do you exchange gifts with your parents?
(Prompt: Almost never; about once a year; several times a year; every other month or so; every month; about once a week; several times a week; almost every day)

Section C: Carer's Description of Filial Support Given to Elderly Parents

"I'll move on to the sorts of services your ...(parent) receives from Fife Region in a moment. Right now I'd like to find out a bit more about the help that you give your parent as well as the help your parent receives from other family members, friends and neighbours."

"First of all, can you tell me how and why you started to care for your elderly parent. (Probe for circumstance surrounding commencement of care and when it all began)

"Can you describe to me what you do for your parent in a typical week" (Prompt for visits, tasks and time).

"And can you give me an idea of the time, physical and emotional effort involved in providing that care for your elderly parent.

"What would you say are the best aspects of helping to care for your elderly parent?

"And what are the worst aspects?

"So, out of all the help that your mother/father receives from the family, who would you say s/he relies upon the most?

"And again thinking about the family, does s/he rely on anyone else? (Probe for details)

"And is there anyone outside the family who provides even more care than you (or main carer nomination) do/es? (Probe for identity and overview of what this person does).

"Moving on to any of your brothers or sisters, which of them would you say helps your elderly parent the most? (Probe whether any help).

"Can you tell me what this sister/brother does for your parent? And how important that help is? (Probe for: day to day care tasks - household and personal care; liaison with SWD and other agencies; arranging and transporting parent to any appointments (e.g. the doctors); providing carer with emotional support; and providing parent with emotional support).

"What about those sisters/brothers who don't help with caring for your father/mother. Why is that? (Prompts: emotional relationships; distance; family and employment circumstances).

"How fair do you consider the present arrangements for looking after your mother/faher to be in terms of what you do and what your brothers/sisters do?

"To what extent do you and your sisters/brothers discuss how your mother/father might best be cared for?

"And if it became necessary, how easy would it be for you to increase what you are doing for your father/mother?

"What about your sisters/broters, how easy would it be for them to increase what they do for your father/mother?

Section D: The Receipt of Formal Services

"Can you explain to me why your mother/father started to receive services from the SWD?

"Can you tell me which services your mother/father needs from the SWD? (Go through checklist of actual services available and check whether parent actually receives services specified by carer).

"What do you think about the levels of each service your parent receives? (Go through list of services received and prompt for adequacy).
"What type of contact do you have with the people who organise and deliver the services your parent receives from the SWD? (prompt: identity; regularity; circumstances; and adequacy).

"Can I check, were you helping your mother/father before s/he started to receive services from the SWD? (probe: tasks done, duration; burden).

"And do the services your mother/faher receives from the SWD affect you and the help you give him/her in any way?

"More specifically, would you say the services from the SWD have increased, decreased or not affected the amount of help you give your parent?

"And how does the help you give your mother/father differ from the help they receive from the SWD?

"So what in your opinion are the best aspects about the services your mother/faher receives from the SWD?

"And what are the worst?

"And which is more important for the following tasks: you and the help you give your parent or the help they receive from the SWD? (help with housework; help with personal care; providing information; meeting other people - not family; providing emotional support; helping parent to remain at home; helping parent to o things for him/herself; helping parent to join in social activities - non family; helping parent to get to appointments - e.g. doctor's surgery.